World Edition 2020/2021

INTERNATIONAL BRAIN TUMOUR ALLIANCE

Brain Tumour

You are not alone on this journey...

Fourth World Summit of Brain Tumour Patient Advocates

Report inside

Also inside...

- The Brain Tumour Patients' Charter of Rights
- New Brain Tumour Groups in Israel & Pakistan
- Rethinking Brain Tumour Drug Development
- Brain Tumours in the Era of COVID-19
- Stereotactic Radiosurgery for Brain Tumours

PLUS:
Stories from our international brain tumour community:
United States
United Kingdom
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Canada, Europe
Japan,
South America
and other regions

GREATER COLLABORATION ■ GREATER KNOWLEDGE ■ GREATER HOPE

International Brain Tumour Awareness Week 2021

International Brain Tumour Awareness Week 2021

The 2021 International Brain Tumour Awareness Week will take place from Saturday, 30th October to Saturday, 6th November 2021

The 15th International Brain Tumour Awareness Week is your chance to highlight the challenges of brain tumours in your own country. We encourage you to organise an activity which will contribute to increased awareness about brain tumours. For example, it could be a walk, a picnic, an information seminar, a scientific conference, a coffee morning, the distribution of a media statement or whatever you think will help to publicise the brain tumour cause and highlight the need for a special response and an increased research effort.

Please register/report your Awareness Week activity by completing this form: **https://theibta.org/sign-up-for-an-event/#awareness**

For more information please visit
www.theibta.org or contact kathy@theibta.org

Contents

- **Re-thinking brain tumour drug development** by Nader Sanai 8
- **Brain tumours in the era of COVID-19** by Martin Glas and Sied Kebir 11
- **Identifying priorities, assessing evidence and driving clinical studies in glioma in the UK** by Robin Grant, Helen Bulbeck, Gail Quinn, Michael Jenkinson and Tess Lawrie 13
- **The Rare Brain Tumour Consortium (RBTC): working together to advance rare pediatric brain tumours** **15**
- **ILAM – the Israeli Association for Brain Tumours** by Keren Gonen 17
- **In conversation with Dr Roger Packer on clinical trials and COVID-19 in the pediatric brain tumour population** Interview by Anita Granero. 19
- **The Pakistan Society of Neuro-Oncology (PASNO) launched** by Syed Ather Enam. 21
- **Welcome to the ISPNO2020 Hybrid Meeting** by Koichi Ichimura and Ryo Nishikawa 23
- **The Brain Tumour Patients' Charter of Rights** 24
- **We have to think of those who succeed** by Fatima. 39
- **European Cancer Organisation and the EU Health Commissioner** 39
- **Meet the Sontag Foundation's recently-appointed Executive Director, Hilary Keeley**. 40
- **Telehealth: what you need to know about a virtual doctor visit** by Brittany Cordeiro. 44
- **In conversation with Claire Karekezi, MD – Rwandan neurosurgeon extraordinaire** 48
- **Report of the 4th Biennial World Summit of Brain Tumour Patient Advocates** by Chris Tse. 51
- **The Lithuanian Brain Tumour Patients and their Caregivers Society: celebrating our fifteenth anniversary** by Aistė Pranckevičienė and Laura Šalčiūnaitė 133
- **Stereotactic radiosurgery for brain tumours** by H Ian Sabin 136
- **Spaeth Family walk to honour three loved ones and raise awareness of brain tumours** 138
- **ZBTA walks in Harare for brain tumours** 142
- **Brain Tumour Research Walks of Hope**. 144
- **IX International Brain Tumour Awareness Day Symposium in Bucaramanga, Colombia** by Gabriel Vargas 145
- **COVID-19 doesn't stop the annual Kortney's Challenge Fun Run/Walk** by Kristen Gillette 150
- **12th Annual Nick Gonzales charity golf tournament and fundraising dinner**. 151
- **Brain Tumour Awareness Day in Argentina** by Alejandra T Rabadan. 153
- **New beginnings: Meagan's Hug** by Elizabeth Becker 154
- **Walking together in 2019 in hope and celebration**. 155
- **GLIOTRAIN: a multi-pronged attack on glioblastoma** by Alice O'Farrell and Annette Byrne. 160
- **GliMR – shedding light on advanced MRI imaging for glioma** by Esther Warnert and Patricia Clement 165
- **Directory of brain tumour patient organisations and initiatives** 168

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Dear Reader,

Who would have thought it?

International travel abandoned. City centres deserted. Shops boarded up. Restaurants shuttered. Curfews imposed. Schools halted. Masks worn. Huge populations working from home. Handshakes and hugs, a distant memory. And worst of all, at the time of writing, over 40 million people have been diagnosed with COVID-19 while, tragically, over one million have lost their lives to the disease.

COVID-19 has paused the world, taken a very heavy human and economic toll and re-shaped it in ways we never thought possible.

But one thing hasn't stopped. And that is the dedication and commitment of the international brain tumour community who have determinedly soldiered on with their crucial work right through this world crisis to ensure that all those living with a brain tumour are not forgotten.

Publication of this year's *Brain Tumour* magazine has been delayed by COVID-19 but not stopped by it either. In this edition, we offer you not only items about COVID-19 and brain tumours, but we also have our usual range of stories from around the world, treatment perspectives, interviews, community news and more. We hope you will find inspiration and hope in these pages, especially during these turbulent times.

With best wishes,

Kathy Oliver

Chair, International Brain Tumour Alliance (IBTA)

We wish to thank the following for their support of the IBTA's work this year.

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Pfizer Oncology
Northwest Biotherapeutics
The Sontag Foundation
Novartis
apogenix
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GW Pharma

Around the World with the IBTA

The IBTA has contacts in 112 countries around the world to whom it makes available its free annual magazine, *Brain Tumour*. During normal times, in non-COVID-19 days, we print 14,000 copies of *Brain Tumour* magazine and send them for free to recipients in these countries and distribute the magazine at major national and international neuro-oncology and cancer conferences. At the moment, due to the COVID-19 pandemic, *Brain Tumour* magazine is being published digitally on www.issuu.com

There is no other magazine like *Brain Tumour* which reaches deep into the international brain tumour community and covers stories from patients, family members, healthcare specialists, researchers, scientists, professional societies and others.

Brain Tumour magazine has readers in the following countries:

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Re-Thinking Brain Tumor Drug Development

Nader Sanai, MD

Francis & Dionne Najafi Chair in Neurosurgical Oncology;
Director, Division of Neurosurgical Oncology;
Director, Ivy Brain Tumor Center, Barrow Neurological Institute, Arizona, USA

Recently, new cancer drugs have generated notable successes in tumor control. For patients with advanced lung or skin cancer, for example, a growing arsenal of approved therapeutics are yielding historical improvements in survival. Why has this surge in successful drug development not yet touched the brain tumor community? At least part of the reason has to do with our ability to translate a successful result from the brain tumor laboratory to the brain tumor patient.

Drug development typically begins with 'preclinical' studies that experimentally treat animals harboring brain tumors. These tumors are generated from genetic manipulation of the animal or direct injection of a human tumor into an animal's brain. A more simplified approach to drug testing entails treating brain tumor cells or lumps of human brain tumor tissue in a Petri dish. At best, these models are loose approximations of a patient's reality. Thus, it is no surprise that laboratory studies have never accurately predicted the results of human brain tumor clinical trials.

Breaching the blood-brain barrier and other pillars of resistance

But replicating the complexities of a human brain tumor in the laboratory is not the only front in this war. For its own protection, the brain is designed to keep things out. This self-defense mechanism, enabled by the 'blood-brain barrier,' is why drugs effective for other human ailments are, thankfully, not detrimental for the brain. In fact, 99% of all new drugs are incapable of crossing the blood-brain barrier. Identifying which new drugs have the potential to gain access to brain tumors is a matter of chemistry. The challenge, however, lies in recognizing which drugs actually succeed at this in patients.

Dr Nader Sanai, Ivy Brain Tumor Center, USA

The most common method of estimating a new drug's capacity for human brain penetration is to administer the drug to an animal and then measure its concentration in the animal's brain and brain tumor tissue. Unfortunately, the assumption that these results will represent the human experience is fraught with risk. Specifically, the blood-brain barrier is assembled differently for every species. So, what penetrates the mouse brain does not necessarily penetrate the human brain. Beyond this structural issue, there is the issue of drug metabolism. Each species processes drugs differently, which means an identical dose (adjusted by body weight) for a mouse and a human can yield two divergent results.

A final pillar of resistance for brain tumors is their diversity. For many other cancers, the biology of each tumor type is very similar from patient to patient. Skin cancer, for example, can be subcategorized into different genetic subtypes, but within each subtype, there is little variation between patients. Brain cancers are far more fluid. Within each patient, tumors are continuously reorganizing with hyper-evolutionary speed. This not only

Right: Members of the multidisciplinary Ivy Brain Tumor Center at Barrow Neurological Institute

Dr. Nader Sanai and Ms. Catherine Ivy at the Ivy Brain Tumor Center in Phoenix, Arizona, United States.

creates a moving target, but it means two patients with exactly the same tumor type and treatment can have wildly different outcomes. In the context of a clinical trial, this adds substantial complexity to identifying drugs that "work".

Drug development for non-brain cancers does not face such harrowing obstacles. Animal models for lung and skin cancer are reliable proxies for the human version. Drug delivery to human lung and skin cancer is not an issue. In contrast, for glioblastoma - the most common brain cancer and deadliest cancer known to man - these realities are central to the drought in new drug development. Worldwide, it has been 20 years since a new drug approval has provided glioblastoma patients with a survival benefit.

The Phase 0 Clinical Trial

The brain cancer community is readying its response. Drug discovery and medicinal chemistry are now in an era of unprecedented productivity and innovation. The pharmaceutical and biotech industries are blossoming, driving the creation of new drugs and new drug companies at a record pace. In 2010, the US Federal Drug Administration (FDA) approved 21 new drugs, yet in 2019, they approved 48. By all indications, the tide will continue to rise as we enter a new decade.

The rush of new experimental drugs for brain tumors, however, still faces the same obstacles outlined above. A more efficient and predictive system for testing is needed. Fortunately, we can borrow a strategy from the medical oncology playbook—the Phase 0 clinical trial. For years, Phase 0 clinical trials have enabled medical oncologists to rapidly identify which new therapies warrant accelerated development and, equally importantly, which new therapies are destined for failure. This specialized strategy for clinical trialling saves both time and money - two commodities the brain tumor community has in short supply.

In its simplest form, a Phase 0 clinical trial asks the same questions that we ask in animal models, except it does so in humans. After administering a small amount of an experimental drug to a patient before planned sampling of the patient's tumor tissue, two critical questions can be answered: (1) Does the new drug reach the patient's tumor in sufficient concentration? (2) Does the new drug hit its intended molecular target in the patient's tumor? In technical terms, the first question assesses the drug's 'pharmacokinetics,' the second question assesses the drug's 'pharmacodynamics.'

For tumors like lung or skin cancer, Phase 0 clinical trials are comparatively straightforward to perform. Because these tumors have no blood-brain barrier, the patient can undergo a simple needle or shave biopsy on Day 1, a single 'microdose' of the experimental drug on Day 2, and another biopsy on Day 3. The trials are fast (the biopsies can be performed as an outpatient) and low-risk (the drug dose is exceedingly low).

For brain tumor patients, however, things are never as simple. Even a biopsy requires drilling through the skull, and a drug 'microdose' is unlikely to traverse the blood-brain barrier. These added complications, however, pale in coåmparison to something else that brain tumor patients are missing: time. Today, the average glioblastoma patient survives for fewer than two years. The Phase 0 clinical trial, as described above, provides many things, including invaluable human pharmacokinetic and pharmacodynamic data essential for intelligent drug development, but it does not provide any hope of a therapeutic benefit for the charitable cancer patient who selflessly ➤

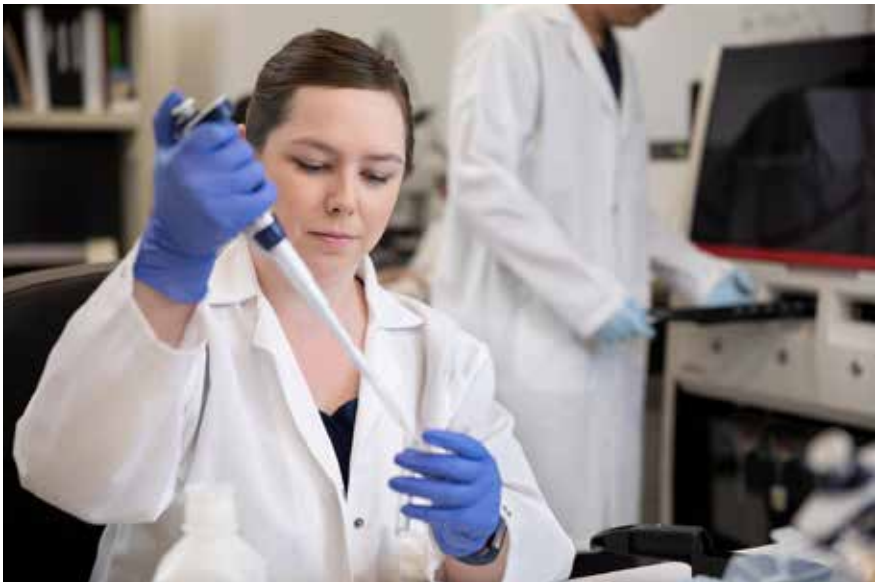
Left: The Ivy Center preclinical modeling team works to assess whether a new drug combination is ready for a first-in-human Phase 0 clinical trial using a patient-derived animal brain tumor model.

enrolls in such a trial. This not only makes it more difficult to fill the trials but, more importantly, it does not provide trial patients with a new therapeutic option.

The Ivy Brain Tumor Center in Phoenix, Arizona

In 2018, the Ben & Catherine Ivy Foundation awarded a $50M grant to establish the Ivy Brain Tumor Center at the Barrow Neurological Institute in Phoenix, Arizona. This not-for-profit, early-phase clinical trials program resides within an academic medical center that operates on over 1,200 brain tumor patients per year. Its sole focus is to adapt the Phase 0 clinical trial concept for these patients. For most Ivy Center Phase 0 trial patients, their journey begins at the time of tumor recurrence, when no proven therapeutic option exists. Based on a match with individual tumor genetics, an experimental drug cocktail is administered for several days prior to a planned craniotomy. For each patient, surgically sampled tumor tissue is assessed for drug penetration and target modulation.

Within days of the operation, we learn whether the regimen will be effective in the patient and, if the answer is 'yes,' the patient continues with treatment. If the answer is 'no,' we have learned critical information without costing the patient an opportunity to pivot to another therapy or clinical trial. Importantly, this Phase 0 trial approach is individualized. Every patient's response to an experimental drug is evaluated in the context of each tumor's individual biology—success or failure is based on direct evidence of pharmacokinetic and pharmacodynamic response.



In the pursuit of a personalized treatment plan for brain tumor patients, postdoctoral fellows in the Ivy Center's pharmacodynamics core perform an antibody test to measure a drug's effect in a Phase 0 trial patient's tumor.

Innovations to clinical trial design alone cannot move the needle unless we have access to suitable new drug combinations. To this end, the Ivy Center has adopted an aggressive stance in its pharmaceutical and biotech partnerships.

Traditionally, the marriage between an academic medical center and a drug company is contentious. Details surrounding financial support, intellectual property, and contracting can plague even the best-intentioned projects, slowing progress to a crawl. A brain tumor clinical trial can take years to complete. To sidestep these landmines, the Ivy Center never requests a penny (from patients or industry) for its clinical trials, nor does it lay claim to intellectual property or downstream revenue. By assembling a specialized, stand-alone legal team unencumbered by the corporate policies of an academic medical center, the lead-in time for planning a new clinical trial can be measured in weeks. With this positive approach to industry partnerships, companies are incentivized to engage the brain tumor market.

Through hard-fought advances in the science and medicine of brain tumor patient care, our community of patients, physicians, caregivers, and scientists is approaching an inflection point. Successful drug development campaigns against other cancers provide a blueprint for efficient bench-to-bedside translation and effective industry collaboration. The Ivy Brain Tumor Center is carving a new road towards accelerated drug development and tailored care for individuals struggling against a perennially mortal adversary. ■

Left: A research technician in the Ivy Center's pharmacokinetics core prepares a patient's tissue sample to determine if a new, experimental drug cocktail has penetrated the patient's blood-brain barrier and reached the tumor in sufficient concentrations.

Brain Tumours in the Era of COVID-19

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The COVID-19 pandemic affected and still affects health care for cancer patients. [1]

COVID-19 is a respiratory illness caused by the newly discovered virus, SARS-CoV-2. The mechanism through which SARS-CoV-2 leads to symptoms – that may be fatal – is quite complex. In simple words, however, SARS-CoV-2 infection leads to the destruction of lung cells, which in turn triggers a local immune response aimed at clearing the infection. While in most cases, this process is successful, in some cases, the immune response does not work properly and itself becomes the problem and becomes the source of severe lung and systemic injury. [2]

Professor Dr Martin Glas

Dr Sied Kebir

Risk factors

Generally, COVID-19 more severely affects elderly people above the age of 65, people with pre-existing conditions, and those with a weakened immune system.

Patients with a diagnosis of brain cancer are susceptible to infections for a multitude of reasons, including a compromised immune system due to the disease itself and due to anti-tumour treatments, such as chemotherapy. In addition, brain tumor patients under active anti-tumour treatment are exposed to inevitable contacts with hospital staff, other patients, or with people during their transit. These factors support the idea that there may be an increased risk of SARS-CoV-2 infection in patients with a diagnosis of brain cancer.

Fear of being potentially exposed to the virus, particularly when visiting hospitals for routine visits or to clarify symptoms of progressing disease and necessary cancer treatment, is widespread. This seems to continue even up to the present day despite the measures that hospitals have taken to ensure the safety of their staff and patients alike. Recent studies, however, clearly indicate that these measures have been very effective, such that - under strict population-wide and institutional safety measures - infection rates in outpatient cancer patients have been shown to be very low and that the continuation of active anticancer therapy and follow-up visits may be still feasible. [3]

Given the aggressiveness of brain cancer, it is critical that treatment initiation and continuation are not hampered by concerns over possible infection with SARS-CoV-2. On the other hand, brain cancer patients should not be exposed to unnecessary risks of contracting COVID-19.

COVID-19 recommendations for brain cancer patients

To provide guidance and ensure proper health care of brain cancer patients in times of COVID-19, various societies, health care professionals, and institutions have published recommendations.

The European Society for Medical Oncology (ESMO), the American Society of Clinical Oncology (ASCO), the European Association of Neuro-Oncology (EANO), the American Society for Radiation Oncology (ASTRO), the Indian Society for Neuro-Oncology (ISNO) and others released recommendations for the management and treatment of patients with primary brain tumours in the COVID-19 pandemic concerning hospital visits, imaging appointments, surgery, radiotherapy, and chemotherapy. [4-9]

Patients with newly diagnosed brain tumours, new-onset or worsening of symptoms or evidence of tumour recurrence should be considered high risk and are advised to visit their doctor in person as soon as possible. For this patient group, it

is recommended to continue imaging (such as MRI), surgery, radiotherapy, chemotherapy, and TTFields therapy (in those countries where TTF is part of the standard of care and is reimbursed) to ensure the best possible treatment and benefit for the patients. Delaying MRI appointments or radiotherapy sessions might lead to tumour growth and worsening of both symptoms and prognosis. Patients with stable neurological symptoms and on adjuvant chemotherapy should consider the possibility of virtual doctors' appointments or telemedicine if the necessary technical equipment is available.

The overall strategy outlined in the ESMO, ASCO, EANO, ASTRO, ISNO, etc. recommendations is to cut down on surgical, radiation, and chemotherapeutic interventions with no clear evidence for survival benefit in order to minimize exposure to SARS-CoV-2 and to provide teleconferences and video consulting whenever possible. Some recommendations, however, such as substituting six-weeks irradiation intervals for four-weeks in malignant glioma, should be considered with caution given the uncertainty of the impact on outcome.

Based on our experience and recent reports, chemotherapy, irradiation and the use of TTFields therapy (where available) seem to be safe and not associated with an increased risk of SARS-CoV-2 infection. [3] For example, instigating measures to reduce personal contact, adopting safer practices and following physical distancing recommendations when delivering devices/equipment as well as using telemedical services to educate and assess patients who use TTFields should significantly contribute to reduce possible SARS-CoV-2 infections.

In addition to the ESMO, ASCO, EANO, ASTRO, ISNO, etc. guidance, brain cancer patients should follow their country's general national COVID-19 recommendations. These include informing your health care provider about symptoms related to COVID-19 infections before your clinic or hospital visit and staying at home if possible in case of symptoms; frequently washing your hands, especially after touching highly used surfaces (such as doorknobs, surfaces on public transport, handlebars); disinfecting hands with hand sanitiser when washing with soap is not possible; wearing a face mask; practicing social distancing whenever possible, commuting by car and avoiding public transportation.

It is important to be aware of risks and symptoms of COVID-19, to follow national directives, and to act accordingly. At the same time, and especially in the case of new or worsening symptoms, it is crucial for the diagnosis, consequent treatment, and prognosis of brain cancer patients to overcome concerns and hesitance for follow-ups and medical consultations.

Timely, high-quality, multi-disciplinary treatment for brain cancer patients should not suffer from restrictions imposed by the current pandemic. Good communication between health care providers and the patient will play a central role to ensure state-of-the-art brain tumour management in the era of COVID-19. ■

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IBTA Survey - Brain tumours and COVID-19: the patient and caregiver experience

The International Brain Tumour Alliance (IBTA) has announced the results of its survey: "Brain tumours and COVID-19: the patient and caregiver experience" which have now been published in the Oxford University Press journal *Neuro-Oncology Advances*.

In April and May 2020, the IBTA, as part of its work with the Society for Neuro-Oncology (SNO) COVID-19 Task Force carried out the first survey within the global community of brain tumour patients and caregivers on how the COVID-19 pandemic had directly affected them. In total, 1,989 participants completed the survey from 33 countries including 1,459 patients and 530 caregivers.

The results serve as a rich resource of data to help individuals and organisations in the international brain tumour community to ensure they continue to fulfil patients' expectations and retain patients' trust by providing accessible, high-quality care, information and support.

The free access paper in *Neuro-Oncology Advances* is available via this link: https://doi.org/10.1093/noajnl/vdaa104

Identifying priorities, assessing evidence and driving clinical studies in glioma in the UK

Robin Grant [1,2], Helen Bulbeck [1,2], Gail Quinn [1], Michael Jenkinson [2] and Tess Lawrie [1]

[1] Cochrane Neuro-Oncology Group - https://gnoc.cochrane.org/neuro-oncology

[2] NCRI brain Group - http://csg.ncri.org.uk/ncri_groups/ncri-brain-group/

Identifying priorities for funding of clinical research in people living with brain tumours is important. In 2003, following acceptance of the report of the UK Medical Research Council (MRC) working party, a commitment was given to involve patients in all aspects of clinical trials. The James Lind Alliance (JLA) Priority Setting Partnership (PSP) enables clinicians, patient advocates, patients and caregivers to work together to identify and prioritise the most important areas of clinical research that could be answered by well-designed clinical studies.

The National Institute for Health Research (NIHR) (UK) funds the infrastructure of the JLA and provides the methodology to ensure that the topics selected are done in a fair and transparent way and that people whose lives have been affected by a brain tumour are involved in determining clinical research priorities. In 2015, the Neuro-Oncology JLA top 10 priority areas for Clinical Research were published:

1. Do lifestyle factors (e.g. sleep, stress, diet) influence tumour growth in people with a brain or spinal cord tumour?
2. What is the effect on prognosis of interval scanning to detect tumour recurrence, compared with scanning on symptomatic recurrence, in people with a brain or spinal cord tumour?
3. Does earlier diagnosis improve outcomes, compared to standard diagnosis times, in people with a brain or spinal cord tumour?

Dr Robin Grant

4. In second recurrence glioblastoma, what is the effect of further treatment on survival and quality of life, compared with best supportive care?
5. Does earlier referral to specialist palliative care services at diagnosis improve quality of life and survival in people with a brain or spinal cord tumour?
6. Do molecular subtyping techniques improve treatment selection, prediction and prognostication in people with a brain or spinal cord tumour?
7. What are the long-term physical and cognitive effects of surgery and/or radiotherapy when treating people with a brain or spinal cord tumour?

8. What is the effect of interventions to help carers cope with changes that occur in people with a brain or spinal cord tumour, compared with standard care?
9. What is the effect of additional strategies for managing fatigue, compared with standard care, in people with a brain or spinal cord tumour?
10. What is the effect of extent of resection on survival in people with a suspected glioma of the brain or spinal cord?

Shortly after the publication of the neuro-oncology JLA research priorities, a working group met the National Institute for Health and Care Excellence (NICE) and developed a strategy to improve quality of clinical studies in the JLA priority areas to improve the likelihood of NIHR and other funding. This included adoption of the top 10 JLA priorities as priority clinical research by the UK neuro-oncology trials research group, the National Clinical Research Institute (NCRI) Brain Tumour Group. This group manages a comprehensive national portfolio of clinical trials and other well-designed studies and fosters translational research in the trial portfolio that enhances the potential for stratified medicine.

The first step in the funding ladder after selecting the priority topics is to perform up to date systematic reviews of the existing evidence base on which to base proposals. Through the Cochrane Neuro-

Oncology Group, and in collaboration with the NCRI Brain Tumour Group, a funding application for Evidence Synthesis was submitted and supported by an NIHR Systematic Review Programme Grant in 2017. This funded a suite of eight complex systematic reviews, categorised into three broad research areas:

A. How do I get a prompt, safe and accurate diagnosis?

1. Interventions to reduce time to diagnosis of brain tumours. DOI: CD013564 (DOI is the Digital Object Identifier, a string of numbers and letters used to identify an article and link to it on the internet)
2. Intraoperative imaging technology to maximise extent of resection for glioma: a network meta-analysis. DOI: CD013630
3. Diagnostic test accuracy and cost-effectiveness of tests for codeletion of chromosomal arms 1p and 19q in people with glioma DOI: CD013387
4. Prognostic value of test(s) for O6-methylguanine–DNA methyltransferase (MGMT) promoter methylation for predicting overall survival in people with glioblastoma treated with temozolomide. DOI: CD013316

B. Shared Decision Making and risk sharing in glioma e.g:
Should I have regular MRI scanning?
Should I delay therapy for my low-grade glioma to prevent late effects?

5. Interval brain imaging for adults with cerebral glioma. DOI: CD013137
6. Long-term neurocognitive and other side effects of radiotherapy, with or without chemotherapy, for glioma. DOI: CD013047

C. Understanding the best treatment when decisions are difficult in GBM
What is the best treatment for GBM in the elderly?
What is the best treatment for GBM after radiotherapy and temozolomide fail?

7. Treatment of newly diagnosed glioblastoma in the elderly: a network meta-analysis. DOI: CD013261
8. Treatment options for recurrent glioblastoma: a network meta-analysis. DOI: CD013579

A word cloud that gives prominence to the key words that appear in the Neuro-oncology JLA PSP'.

The systematic reviews of evidence helping to answer these questions are complex and are available from the Cochrane Neuro-Oncology website https://gnoc.cochrane.org/neuro-oncology The formal launch of the suite of eight complex systematic reviews will be published and disseminated in November 2020.

The systematic reviews have already helped support many recently funded, NCRI adopted, studies including:

KEATING - KEtogenic diets as an **A**djuvant **T**herapy **IN G**lioblastoma

BT LIFE - Brain **T**umours – **L**ifestyle **I**ntervention and **F**atigue **E**valuation

BRIOChe - Brain **R**e-**I**rradiation **o**r **Che**motherapy: a Phase II trial of re-irradiation or chemotherapy for recurrent glioblastoma.

FUTURE GB - Functional and **U**ltrasound g**u**ided **Re**section of Glioblastoma

BRAIN MATRIX - A **BR**itish feasibility study of molecular stratification and targeted therapy to optimize the clinical m**A**nagement of pat**I**e**N**ts with glio**MA** by enhancing clinical ou**T**comes, **R**educing avo**I**dable to**X**icity, improving management of post-operative residual & recurrent disease and improving survivorship

The systematic reviews are also supporting other studies in development:

MERIT - Maximising **E**xtent of **R**esection using **I**ntra-operative MRI in brain **T**umours

SHIPPING - Scanning **H**eadache to **I**dentify **P**ositive **P**redictive factors for use **in G**uidelines

At each stage in the JLA process of identifying the clinical research priorities, applying for funding of systematic reviews, ensuring that lay summaries are simple and understandable to everyone, developing future research studies through the NCRI, there is a valuable role for the patient voice and advocates. These strengthen submissions and ensure that clinical research funding is targeted in meaningful clinical areas and not only niche academic basic or translational science.

We would like to thank all patients, caregivers and public representatives in the Neuro-Oncology JLA, Cochrane Neuro-Oncology Group and NCRI brain group for making this programme a success. ■

The Rare Brain Tumour Consortium (RBTC): working together to advance pediatric rare brain tumours

Dr. Annie Huang, MD, PHD, Principal Investigator

Arthur and Sonia Labatt Brain Tumour Research Centre (BTRC),
The Hospital for Sick Children (SickKids) Research Institute, Toronto, Canada

Dr. Salma Al-Karmi, PhD, Coordinator

The Rare Brain Tumour Consortium, Toronto, Canada

Our story

The problem with rare diseases is that they are rare.

Now, consider that all childhood tumours are rare, representing 0.5% of all cancers. As such, pediatric diseases labelled as "rare" are even more scarce!

Our story began in 2002, when we did not have the resources, materials, funds, or manpower to study rare pediatric brain tumours. As with many rare diseases, these diseases were mysterious and at the time, rare brain tumours did not receive much attention. This was mainly because the medical community could not define what these tumours were, and we did not know much about them. Consequently, children were often misdiagnosed and inappropriately treated. At a single hospital, the occurrence of these tumours was like finding a needle in a haystack. How could we study something so inaccessible?

To help improve survival, treatment, and the understanding of these rare diseases, an international collaborative effort was required to generate the tools and the data required for meaningful scientific studies.

The Rare Brain Tumour Consortium (RBTC) is an international network of clinicians, researchers and patient advocates working together to help further and advance knowledge on pediatric rare brain tumours. Initially, the RBTC was supported solely from patient family funds which provided us with the primary seed money that sparked our studies. Today, the registry has now become one of the largest of its kind with over 120 international sites in 25 countries and approximately 3000 patient samples with associated clinical data. The RBTC has become an internationally recognized network and resource with an impressive track-record for redefining these diseases. Through this collaboration, our work had led to break-through discoveries that have directly impacted patient care, resulting in improved diagnostics, advancing therapeutic options for patients, and better outcomes.

Dr Annie Huang

Dr Salma Al-Karmi

What we do

We can now define rare pediatric brain tumours as brain tumours diagnosed in about 5-10% of children for which still, there exists very little information. These include:

- Embryonal tumour with multiple rosettes (ETMR) which include:
  - Embryonal tumour with abundant neuropil and true rosettes (ETANTR)
  - Medulloepithelioma
  - Ependymoblastoma
- Atypical teratoid rhabdoid tumour (ATRT)
- Pineoblastoma
- Other embryonal brain tumours formerly known as primitive neuroectodermal tumours (PNET or CNS-PNET)

The RBTC collects several biomaterials including tumour tissue, cerebrospinal fluid (CSF), and blood from patients with rare pediatric brain tumours. These specimens are mainly used to generate scientific data

to learn about tumour behaviour and discover new therapeutics or drugs to treat patients. We also house an extensive unparalleled clinical registry which has carefully curated clinical data and is securely stored in an electronic database. These records permit researchers to establish correlative studies that can help clinicians better understand the biology of these tumours in relation to patient profiles.

What we have done

The resources provided by the RBTC have resulted in multiple ground-breaking genomic publications. They have enabled deeper scientific programs worldwide that are informing changes in therapeutic approaches.

■ **Discovery of epigenetic subgroups with variable therapeutic sensitivities in atypical teratoid rhabdoid tumours (ATRT)** (Torchia et al. *Lancet Oncology* 2015, Torchia et al. *Cancer Cell* 2016).

• We reported the first and largest study of its kind describing ATRT as three distinct genetic subtypes with varying therapeutic sensitivities and clinical profiles. This meant that ATRTs were not a single disease as once believed. These significant findings are helping to refine and tailor treatments for patients.

■ **Discovery of C19MC as a novel biomarker in an aggressive subgroup of CNS-PNET** (Li et al. *Cancer Cell* 2009).

• We discovered that a lethal subset of CNS-PNET tumours were characterized by a highly replicated (amplified) DNA segment called C19MC (a polycistronic miRNA locus). These tumours are now recognized by the World Health Organization (WHO) as a distinct entity termed embryonal tumours with multiple rosettes (ETMR) with the C19MC amplification as its defining feature and target for subsequent investigations.

■ **Discovery of LIN28 as a diagnostic marker for histological sub-classes of ETMRs** (Spence et al. *Acta Neuropath.* 2014, Spence et al. *Neuro-Oncology* 2014; Picard et al. *Lancet Oncology* 2012, Korshunov et al., *Acta Neuropath.* 2012).

• We found that upregulation of a gene known as LIN28 correlated with C19MC amplification in ETMRs. This finding brought forth the development of a new, inexpensive diagnostic tool (LIN28 immunohistochemical staining) for these tumours and is being used internationally as standard-of-care.

■ **Personalized therapies for ETMR and ATRT** (Sin-Chan et al. *Cancer Cell* 2019, Torchia et al. *Cancer Cell* 2016)

• Recently, we described in ETMRs a novel oncogenic circuit (C19MC-Lin28A-MYCN) that drives its aggressive behaviour. Our findings create a new avenue for therapies, demonstrating that this circuit is particularly sensitive to a new class of drugs known as bromodomain (BET) inhibitors. Similarly, we identified several new effective drugs, including dasatinib for a subset of ATRTs using computational methods with preclinical validation.

■ **Radiation sparing treatment protocol for ATRTs**

• There is a great need for radiation-sparing therapies for infant patients in order to avoid the devastating neurocognitive effects of radiation exposure to the developing brain. Using the RBTC's clinical registry, we have developed a unique, radiation-sparing protocol for these patients that is now standard of care at SickKids and the majority of Canadian centres, and its use is requested in centres in the USA, Europe, and Asia. A prospective trial based on our protocol is in development for the Pacific Pediatric Neuro-Oncology Consortium (PNOC).

■ **Discovery of molecular subgroups with distinct biological and clinical features in pineoblastoma** (Li et al. *Acta Neuropath.* 2019):

• Gathering tumour samples from close to 30 centres of the RBTC, we constructed one of the largest collections of this highly aggressive childhood brain tumour that arises from the pineal gland. Analyzing this rich dataset, we discovered that pineoblastoma is made up of five different subgroups. Each subgroup is characterized by different gene mutations and patient features like age and survival. These important findings will help in the design of future clinical trials and the search for better treatments that will improve survival rates and reduce side-effects for children affected by pineoblastoma.

We are very pleased to announce the launch of our new webpage for the Rare Brain Tumor Consortium (RBTC): https://lab.research.sickkids.ca/annie-huang/rbtc/. Visit our website and learn about new developments in understanding and treatment of rare brain cancers. Enroll your child/your patient - their information will be used to help them and other children suffering from these challenging diseases.

ILAM - The Israeli Association for Brain Tumors

Keren Gonen, PhD

Chief Executive, ILAM

ILAM - The Israeli Association for Brain Tumors - was established in August 2019 by family members of patients with brain malignancies, neuro-oncology health care providers, and social workers.

Brain tumor patients and their caregivers face daily struggles that influence not only the patients but their entire family. Patients deal with physical disabilities, emotional upheaval and draining treatments. Additionally, patients and caregivers are forced to deal with legalities and bureaucracy in order to receive much-needed social benefits. The aim of ILAM is to provide support for patients, families and caregivers on all of these fronts.

ILAM provides emotional support, access to medical knowledge, and assistance with obtaining benefits.

Emotional support

ILAM offers free counseling for patients and their caregivers. In addition, ILAM operates a WhatsApp support group, managed by two glioblastoma patients and the association Chief Executive Officer, Keren Gonen Ph.D. The association goes to great lengths to fulfill patients' dreams, for example arranging meetings with national celebrities.

Access to medical knowledge

ILAM's website and Facebook page provide up-to-date information about brain tumors and clinical trials and publish interviews with Israeli physicians from the neuro-oncology field. ILAM has an advisory medical committee that includes leading Israeli neurosurgeons, neuro-oncologists and radiation oncologists. The medical committee members are: Alexandra Amiel MD, Andrew Kanner MD, Lior Zach MD, Chen Makranz MD and Sagi Harnof MD. ILAM also plans to hold professional conferences.

Dr. Keren Gonen (Ph.D) is the CEO of ILAM; she is a clinical social worker and psychotherapist and an expert in the treatment of trauma and anxiety

The medical committee of ILAM is led by Dr. Shlomit Yust-Katz (above), Head of the Neuro-Oncology Unit, Davidoff Cancer Center. Dr. Yust-Katz trained in neuro-oncology at MD Anderson Cancer Center, Houston, Texas, US.

Social security benefits

ILAM collaborates with attorneys, accountants, universities, legal clinics and various associations in order to help patients become aware of their social benefits and legal rights. The association assists patients and their families with the often-cumbersome bureaucratic processes.

Although the association is relatively young, it already has accomplished significant achievements and continues to deal with relevant issues:

- ILAM dramatically influenced the decision to include OPTUNE technology in the Israeli medical services basket since January 2020 for the treatment of patients with newly-diagnosed glioblastoma. Within the association,

Professor Deborah T. Blumenthal, a member of ILAM's medical advisory committee, trained in neurooncology at Memorial Sloan- Kettering Cancer Center in New York City and came to the Tel-Aviv Medical Center in Israel in 2005, after directing the Neuro-Oncology Unit at the Huntsman Cancer Institute/University of Utah for seven years.

many meetings were held with the directors of the Ministry of Health and national politicians. Silent demonstrations were held outside the Health Basket committee office. Additionally, members of the association took part in various committees in Congress in order to advance this issue. Today the association deals with insurance companies regarding fulfilling the right to receive treatments.

■ Another important issue with which ILAM is currently involved is the recognition of GBM patients as having permanent full disability status from the time of diagnosis, which allows for a monthly stipend and legal rights from the Israeli National Insurance Institute.

The current policy defines newly-diagnosed GBM patients as having a temporary disability for one year, after which the patients are obligated to appeal to additional medical committees for the continuation of their temporary disability status. ILAM presented a position paper to the Director General of the National Insurance Institute requesting additional benefits for every glioblastoma patient - effective from time of diagnosis - since the onset of clinical deterioration can be rapid.

ILAM's future plans include expanding its activities, increasing its influence on the well-being of our patients and caregivers, and creating collaborations with international brain tumor associations. ■

The Brain Tumour Patients' Charter of Rights (see pages 24-38) has worldwide relevance and sets out an aspirational framework for improving healthcare systems and communications.

INTERNATIONAL BRAIN TUMOUR ALLIANCE

To ensure that you receive the IBTA's monthly e-News and your annual copy of *Brain Tumour magazine*, you can subscribe to these publications at https://theibta.org/our-publications/#e-News

To read about the IBTA's vision, mission, purpose, values and principles, please visit https://theibta.org/our-vision-mission-purpose-values-and-principles/

In conversation with Dr Roger Packer on clinical trials and COVID-19 in the pediatric brain tumor population

Interview by Anita Granero, Founder/President

Oscar's Angels France and Oscar's Angels Italia

Roger J Packer, MD is Senior Vice President of the Center for Neuroscience and Behavioral Medicine and is Director of both the Gilbert Neurofibromatosis Institute and the Brain Tumor Institute of Children's National Hospital in Washington DC, USA.

He is involved in clinical and applied basic science research and is principal investigator (PI) at Children's National for the Pediatric Brain Tumor Consortium (PBTC), formed under the auspices of the National Cancer Institute (NCI).

Anita Granero is Founder/President of Oscar's Angels France and Oscar's Angels Italia and also serves as a Senior Advisor to the IBTA focussing on the pediatric brain tumour community. Anita recently welcomed Dr Packer to the Oscar's Angels Italia's Scientific and Ethics Committee. Here, Anita discussed with Dr Packer some of the ramifications of COVID-19 in relation to the field of pediatric neuro-oncology and his thoughts on patient advocacy.

Anita Granero (AG): Dr Packer - what are the challenges and risks that pediatric neuro-oncology and neurofibromatosis patients have to face with the COVID19 pandemic?

Roger Packer (RP): As regards challenges that the pediatric neuro-oncology and neurofibromatosis communities will have in the COVID-19 era, the simple answer is that children with acute neuro-oncologic needs including immediate appropriate therapy must receive that treatment even in the COVID-19 crisis. Children and their families should not be afraid to access care and the institutions providing this care must be flawless in their ability to make the environment as safe as possible for them. Childhood brain tumors do not wait for crises like COVID-19 to disappear.

There are some surveillance procedures, like routine MRI scans, that can possibly be delayed a few weeks to limit risk of exposure, but needed therapies should not be delayed. These therapies include appropriate surgery, management of hydrocephalus, radiation therapy or chemotherapy. [At our institution] we have taken the stance to continue clinical and translational trials if they are the best available alternatives for the child.

Dr Roger Packer

If a COVID-19 vaccine becomes available it will likely be quite safe for children with brain tumors. Those undergoing active treatment who are immunosuppressed may not be able to benefit fully from the vaccine because their immune system will not mount an adequate response. However, if the vaccine is a "killed" viral vaccine and does not include live viral particles, it should be safe for children.

AG: Turning to clinical trials, why are they so important for children with brain tumors?

RP: Clinical trials are of outmost importance for the pediatric patient. If done correctly they will offer the patient the best available treatment plus additional therapy which may make treatment either safer and/or more effective. Thus, clinical trials should have direct benefits for the patient as it has been shown that the highest quality of care can occur within the clinical trial where all reasonable variables are being closely monitored.

At the same time at a more altruistic level, clinical trials are the only way we are going to make progress in the management of childhood brain tumors for future patients. For many brain tumor types, treatment is suboptimal as regards control of the disease and for other types, there are side effects associated with treatment that have both transient and permanent risks.

AG: What are some of the challenges in pediatric clinical trials?

RP: There are many challenges including being sure that the trial is the appropriate one for that child, that all potential side effects are being monitored carefully and

Anita Granero of Oscar's Angels Italia (right) with Dr Roger Packer

that children and families are followed carefully to determine how effective the treatment is. At times it is difficult for the family and the child to access drugs because they are only available at some highly-specialized institutions and other times families are searching for clinical trials that may not be available for that disease.

The trials are a commitment for the families as they have to take the agents outlined in a very specific manner, they may have to travel long distances, and may need more follow- up to not only monitor that the trial is working, but also possible treatment-related toxicities.

AG: Why does research on childhood brain tumors seem to be behind in comparison to other tumors?

RP: Research seems to be behind in childhood brain tumors for a variety of reasons. Although childhood brain tumors are the second most common form of solid tumor and the leading cause of pediatric-related cancer morbidity and mortality, each individual type of pediatric brain tumor is relatively uncommon. For these reasons, most studies have to be done at many institutions to try to get usable information in an efficient manner.

Until recently the tools available to study the brain and the molecular genetics of brain tumors were not available. Now with better neuro-imaging including enhanced MRI techniques and the rapid development of molecular genetic tests that can be applied to very small portions of tumor, progress can be made more rapidly.

Also, these tumors, given their rarity, may be overlooked by national funding agencies. Overall pediatric brain tumors are one-tenth as common as adult brain tumors, but are different and can be treated more successfully.

AG: In your opinion, how important is patient advocacy?

RP: For all the above reasons, advocacy is of crucial importance: explaining why funding is needed; that new tools are now available to study these tumors; that new therapies are available; that new therapies must be studied carefully in children with brain tumors; that results in adults cannot be used to assess efficacy or risk in childhood brain tumours; and that, in total, these tumors are the leading cause of childhood-associated mortality and morbidity.

AG: Dr Packer, we're extremely excited to have you join the Scientific Committee of Oscar's Angels. What are your thoughts on joining this committee?

RP: It is my pleasure to join the Scientific and Ethics Committee of Oscar's Angels Italia. I am a pediatric neurologist, who has had the honor to care for thousands of children with brain tumors and has had and continues to have the opportunity to develop innovative treatment protocols for children with brain tumors over the past decades.

I have personally witnessed the bravery of children with brain tumors and the dignity and kindness of their families. Organizations like Oscar's Angels Italia are critical in the fight against childhood brain tumors and I am pleased to support this organization and the Bambino Gesú Pediatric Hospital (OPBG) in Rome. It is this type of partnership between organizations, families, hospitals, nurses and physicians that allows us to offer the best care for children stricken with brain tumors and to make real progress in improving their lives and in finding a cure for those dealing with these devastating diseases. ■

Dr Danny Chan from CUHK Otto Wong Brain Tumour Centre in Hong Kong writes that 2019 saw a record-breaking 12th edition of their Braintrekking event which began in 2007. Dr Chan said: "The spirit is still growing in Hong Kong and we had over 550 trekkers completing 1946 km during the walk which has been donated to the IBTA's Walk Around the World for Brain Tumours." ■

The Pakistan Society of Neuro-Oncology (PASNO) launched

Syed Ather Enam, S.I.
MD, PhD (USA), FRCS (Ire), FRCS (Can, SN), FRCS (Glas), FACS (USA)
(Diplomate American Board of Neurological Surgeons) Professor of Neurosurgery
Chair, Department of Surgery
The Aga Khan University, Karachi, Pakistan

Global Neuro-Oncology: Need of the Hour

In the present day, while technology has accomplished advances in seemingly insurmountable circumstances, disparities in healthcare exist in many parts of the world. There is an unmet need for oncological and surgical care worldwide, and this growing burden needs to be addressed with a sense of urgency. In this context, neuro-oncology needs special consideration because of its unique issues. Management of brain tumors is expensive and time-consuming and can leave the patient more disabled than many other tumors. This is further complicated by a lack of resources, making the situation more challenging to deal with in a country like Pakistan.

The challenges of neuro-oncology in Pakistan

Neuro-oncology has mainly been ignored as a specialty in Pakistan. This unmet need emanates from many factors, such as a shortage of specialized centers, inadequate training, a lack of standards in many healthcare centers, inadequate spending on health by the government, out of pocket payments by the patients, and long distances patients need to travel for adequate treatment. As a result, not only do our brain tumor patients continue to receive delayed or suboptimal care, but the skills of our medical teams remain deficient.

Professor of Neurosurgery, Dr. Syed Ather Enam, S.I., Founding President of PASNO, the Pakistan Society of Neuro-Oncology

To make the process of brain tumor management more accessible and affordable for all patients, appropriate research is needed. This research needs to be relevant to the socio-economic condition of the region. This can be addressed from many angles, such as artificial intelligence, telecommunication, liquid biopsy, and cheaper precision medicine, to name a few. One of the foremost strategies is to know the nature of the beast. For that, registry data and molecular epidemiology are essential.

The Pakistan Brain Tumor Epidemiology Study (PBTES) conducted by the Pakistan Brain Tumor Consortium (PBTC) has been initiated. Although the data is being collected, preliminary findings from the study suggest that Pakistan doesn't have as many high-grade tumors as the developed world, but it seems that the brain tumor patients in Pakistan tend to be younger. It also appears that many brain tumor patients are receiving fragmented care in Pakistan. While surgery, chemotherapy, and radiotherapy can be carried out at different centers, it all needs to be orchestrated from one expert hub to obtain the best results. Studies and collaboration like these will stimulate research and come up with solutions to improve brain tumor patients' care not only in Pakistan but in other low-middle-income countries (LMICs).

We need improvements and disruptive innovations to change the landscape of brain tumor management in LMICs. With these solutions, a wholesome protocol can be established to manage brain tumors in LMICs – hence, the emergence of **Global Neuro-Oncology.**

It was for this necessity that the Pakistan Society of Neuro-Oncology (PASNO; www.pasno.org) was founded with the following vision and mission:

VISION: To nurture and produce leaders in Global Neuro-Oncology

MISSION: To improve the care and treatment of brain tumor patients in Pakistan and the region. We achieve this by enhancing public awareness of neuro-oncology, organizing academic activities for professionals, facilitating multidisciplinary collaboration to stimulate locally relevant research, and networking with neuro-oncologists around the world.

Endorsed by major neuro-oncology societies

PASNO is a multidisciplinary platform spanning researchers, neurosurgeons, oncologists, radiation oncologists, pathologists, radiologists, allied health professionals, and basic scientists in neuro-oncology. Platforms like PASNO are coming up in other parts of the world and play a key role in bringing together experts from various cancer specialties to ensure patients' comprehensive and optimum care.

PASNO has received endorsements from many neuro-oncology societies across the world, including the Society for Neuro-Oncology (SNO) based in the United States, the European Association of Neuro-Oncology (EANO), the Asian Society for Neuro-Oncology (ASNO), the World Federation of Neuro-Oncology Societies (WFNOS), the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA), Congress of Neurological Surgeons (CNS) based in the United States and the International Stereotactic Radiosurgery Society (ISRS).

We aim to have membership open to professionals from Pakistan as well as outside Pakistan. Through PASNO, we plan to host academic activities.

One such important activity needs to be mentioned here.

PASNO's 1st Annual Neuro-Oncology Symposium

The Inauguration of PASNO was orchestrated with the 1st Annual Neuro-Oncology Symposium (1ANOS) in Pakistan (September 4-6, 2020). More than 50 speakers from 13 countries enlightened more than 1400 registered attendees. New developments in the field were discussed at the meeting, including precision medicine, molecular diagnosis, state of the art operative techniques and technologies, and the potential of artificial intelligence to improve the diagnosis of brain tumors.

Participants in the inaugural session of the seminar had the unique opportunity to hear the perspective of brain tumor patients and caregivers, which does not usually happen in academic meetings. The fundamental role of PASNO is to improve the care and treatment of brain tumor patients. This feature will remain as one of the central aspects of future ANOS meetings.

PASNO has also taken under its wings the Brain Tumor Foundation of Pakistan, which is primarily dedicated to the needs of patients and their families and caregivers. ■

For further information about PASNO and the Brain Tumor Foundation of Pakistan, please visit www.pasno.org

Subscribe to the IBTA's regular electronic news bulletin.

Visit www.theibta.org

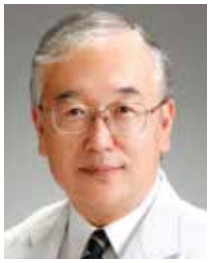
Welcome to the ISPNO2020 Hybrid Meeting

COVID-19 has changed the world. Our hearts go out to those of you whose lives have been profoundly affected by the pandemic.

However, COVID-19 cannot stop our science. We are pleased to inform you that ISPNO2020 will go hybrid, combining an in-person and virtual meeting.

We have a fantastic line-up of the top clinicians and scientists as keynote speakers for all major topics of paediatric neuro-oncology. They will all give their lectures live online and answer your questions real-time in the live streaming program. All live talks are scheduled according to the time zone of the speakers.

You can also watch all Education Day lectures and accepted abstracts in the on-demand program. The on-demand program will open on December 14, 2020, until February 13, 2021. This will give you plenty of time to watch the presentations and ask questions. And for those of you who cannot watch the live lectures real-time, all keynote/special lectures will be recorded and broadcast in the on-demand program within two weeks of the meeting. There will be late-breaking presentations about COVID-19 and paediatric brain tumours, the results of land-mark clinical trials, among many others.



Above left: Koichi Ichimura, M.D., Ph.D, Chair of ISPNO2020, Chief - Division of Brain Tumor Translational Research, National Cancer Center Research Institute, Tokyo, Japan

Above right: Ryo Nishikawa, M.D., Ph.D., Vice Chair of ISPNO2020, Professor at the Department of Neuro-Oncology, Saitama Medical University International Medical Center, Saitama, Japan

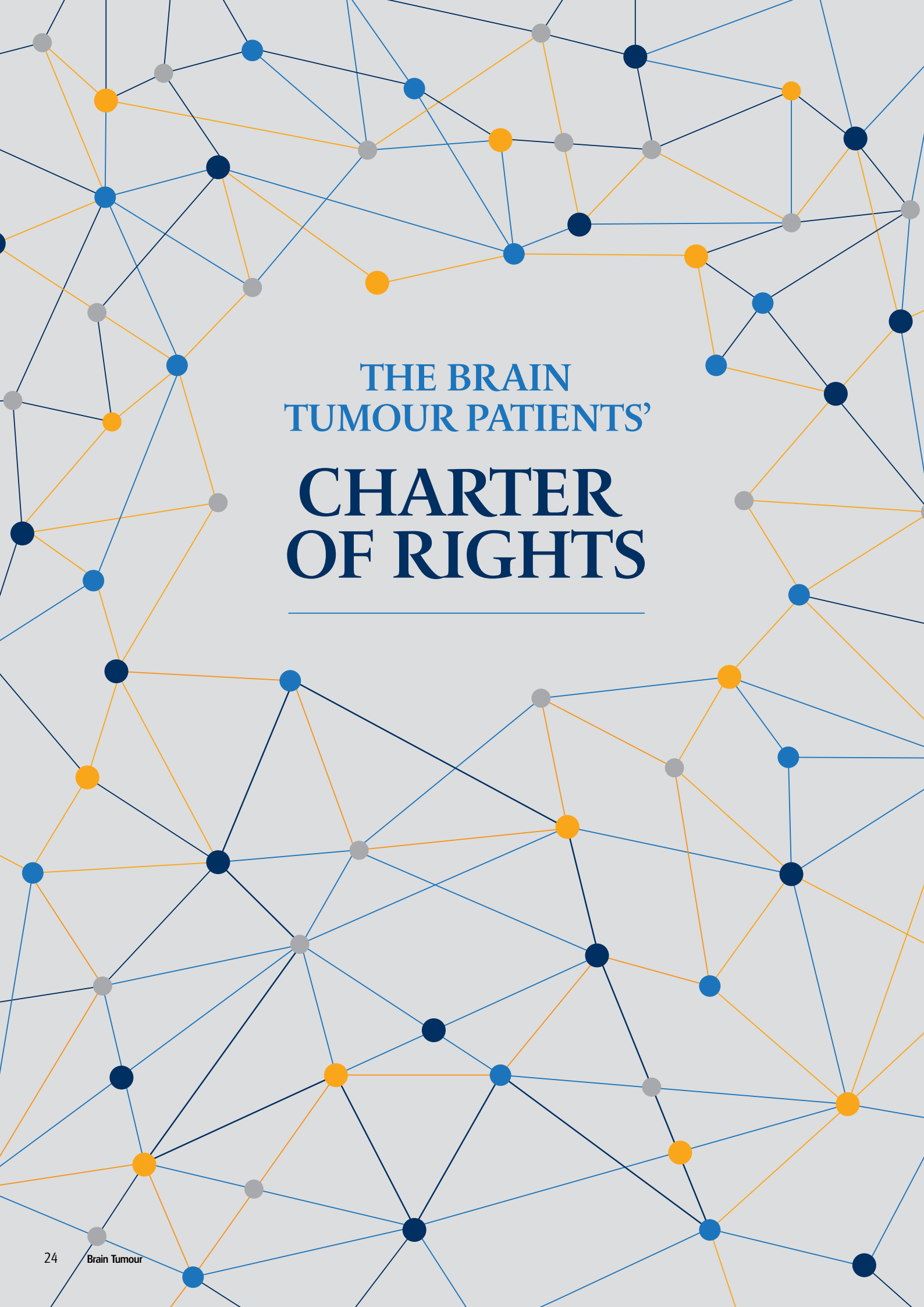
The hybrid meeting is a great opportunity to join the ISPNO2020 meeting remotely for those of you who cannot travel. The registration fee is low, and we offer further discounts to the participants from low/lower-middle income countries.

And for those of you who can take part in the meeting in person, we will be waiting for you in Karuizawa!

We look forward to seeing you at ISPNO2020, virtually or in person ■

Koichi Ichimura Chair

Ryo Nishikawa Vice Chair.



THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

PURPOSE OF THIS CHARTER

To achieve the best possible health and quality of life outcomes for adults and children living with a brain tumour. To represent an aspirational ideal against which quality standards, policies and practices are developed, monitored and delivered.

INTRODUCTION

There are a number of documents dealing with patients' rights, some of which relate to the rights listed here. This Charter has been drafted from the point of view of the brain tumour patient and caregiver with particular consideration for the difficulties which can arise while living with a brain tumour. This Charter has been created through a multi-stakeholder, collaborative and iterative process and is a living document, subject to annual review.

It is hoped that this Charter will have worldwide relevance. We are mindful that many countries lack basic health, research and manufacturing facilities and the specialists and treatment centres with the capacity to deliver the most modern scientific evidence-based care for brain tumour patients. The Charter therefore represents an aspirational ideal which we should work towards and we hope and expect that it will prompt productive discussion and debate to help initiate positive change.

Importantly, the Charter provides a detailed framework for the achievement of policy objectives which brain tumour patient advocacy organisations can use to support their efforts. It can also be used by individual patients and caregivers to underpin the things that matter to them on their brain tumour journeys. The Charter is also meant to be a positive tool that can be used by other sectors of the international brain tumour community.

The Charter can provide everyone with an aspirational framework for improving healthcare systems and communications – goals which we hope will help reduce inequalities from country to country. The Charter is not intended to detract from or criticize the sterling work being carried out every day around the world by researchers, healthcare professionals and others.

We invite those living in developing countries – where many of the aspects of this Charter will not be easily attainable – to select those aspects of this document which are achievable in their own regions and to focus on those to help secure better outcomes for brain tumour patients.

While asserting these rights we acknowledge that no rights can exist in human society without responsibilities.

NOTES

1. *This Brain Tumour Patients' Charter of Rights is not a guarantee of these rights, nor is it legally binding.*
2. *This is the current version of The Brain Tumour Patients' Charter of Rights but as a living document, it is also subject to annual review, and a procedure for the Charter's further evolution will be established.*
3. *Please see the attached appendix to this document which lists the brain tumour charities and not-for-profits, professional neuro-oncology societies and other organisations who have ratified The Brain Tumour Patients' Charter of Rights and given permission for their logos to appear on this document.*

1. ACKNOWLEDGEMENT AND RESPECT

I shall have the right to:

a) access health care designed to reduce the burden of my brain tumour

b) be acknowledged as a person living with a brain tumour

c) be treated as an individual

d) describe myself - whether I am an adult or a child living with a brain tumour - with whatever terminology I feel comfortable with

e) be heard and acknowledged, even if the health care professional does not necessarily agree with my position or perspective

f) be respected as a significant partner in my own care and an expert in my own needs and experience

g) not be discriminated against in my community or my workplace or indeed anywhere at any time because I have a brain tumour

h) maintain hope and to be supported in that hope by my medical team and others responsible for my care, no matter what the diagnosis and prognosis

2. APPROPRIATE INVESTIGATION OF SIGNS AND SYMPTOMS

I shall have the right to:

a) information and education about brain tumours

b) my concerns about my health to be investigated promptly by doctors with appropriate training and experience in neuro-oncology, neurology, neuro-surgery and psychosocial health.

c) a clear explanation of medical imaging done of my brain and brain tumour and the different scanning and assessment techniques and what they can and cannot tell us

d) a clear explanation of the options for treatment of my brain tumour, e.g. surgery, radiation, chemotherapy, clinical trials etc, including the associated risks

e) my tissue/biopsy sample to be analyzed by an experienced neuro-pathologist using validated pathological/diagnostic tests (including biomarker assays) in order to provide me with a correct diagnosis

f) provide informed consent about the use of my resected tumour tissue and, if I have donated/stored brain/tumour tissue or any other bio-specimen for research or other purposes, to know if my tissue sample may be accessed for future treatment decisions and research

3. A CLEAR, COMPREHENSIVE, INTEGRATED DIAGNOSIS

I shall have the right to:

a) a timely referral to a specialist health care provider of my choice

b) receive a prompt and accurate diagnosis (based on an integrated analysis of my tumour tissue using the World Health Organization's most up-to-date classification of brain tumours, and a clinical presentation) which should be conveyed to me in a clear and compassionate manner

c) ask questions about my diagnosis and receive appropriate answers in terms I can understand

d) be accompanied to my diagnosis appointment and any subsequent appointments during the course of my treatment by a family member, close friend or other designated caregiver

e) an interpreter, if the diagnosis is delivered to me in a language in which I am not fluent

f) be proactively involved in all of the decision-making processes relating to my diagnosis and subsequent care

g) take notes in my medical appointments for the sake of clarity and as an aide memoire. Further - but only if I first get all necessary permissions to do so - to record my medical appointments.

h) request and access other opinions at any stage of my care and treatment and to be informed by a specialist if he/she believes they are unable or unwilling to perform an operation, or administer a therapy

i) be given as detailed a prognosis as possible, if requested, which includes information regarding quality of life, side effects of treatment, potential for late effects of treatment and probability of survival

j) a complete copy of all the notes taken in relation to my diagnosis by my medical providers that go into my medical records

4. APPROPRIATE SUPPORT

I shall have the right to:

a) clear, unbiased, honest, comprehensive and timely information that will help me make the difficult decisions with which I will be faced. I also have the right to challenge this information and seek clarification about anything that I do not understand

b) access decision-making tools to enable me to make the right choices for my situation

c) support from a care coordinator or brain tumour journey navigator (i.e. a specialist nurse, social worker or other trained person)

d) be offered information on legal issues that I may need to consider, for example power of attorney, guardianship of children, living wills, advance directives, etc

e) be offered appropriate information about returning to work or school and the laws in my country that govern employing or educating people with disabilities

f) participate in a brain tumour support group if one exists in my local area, attend one virtually or have the opportunity - if I wish - to establish one if it doesn't yet exist

g) be told about local, regional and international brain tumour patient advocacy organisations to whom I can turn for advice and further support

5. EXCELLENT TREATMENT AND HIGH-QUALITY FOLLOW-UP CARE

I shall have the right to:

a) be informed about all available relevant treatment options, in my country of residence, whether (or not) the cost of delivering such treatments are reimbursed by insurance or other third parties

b) share with my treating doctors the decision-making process in selecting the best treatment/s for me, taking into account the level of risk I am prepared to take

c) access treatments based on need – not on my ability to pay for it

d) receive the accepted international standard of brain tumour care, regardless of my age, race, economic background, disability, beliefs or gender

e) receive emergency treatment to stabilise my condition at any point in my brain tumour journey

f) continuity of care from the moment of diagnosis through treatment, recovery, disease progression, long-term survival and end of life. If I am a pediatric patient, continuity of care also includes transitioning to adult follow-up care.

g) be treated in a healthy and safe environment where quality standards are imposed, monitored and met

h) have my medical treatment conducted in accordance with the highest standards of ethical practice.

i) ask for and be provided with copies of all notes and data which go into my medical record, including radiology reports, pathology reports, genetic analyses, etc., as well as digital copies or film copies of all of my scans, and to be recognised as the 'owner' of these records

j) multidisciplinary care, which may include - apart from my core medical team's help - support from other specialists such as physiotherapists, speech and language therapists, psychosocial therapists, social workers, occupational therapists and others

k) be informed if clinically-relevant delays in my treatment are expected and to be informed of alternative service providers who may be able to provide treatments sooner

l) review with my doctor the possibility of using other treatments, experimental or otherwise, in addition to (or instead of) the standard of care

m) be fully informed of all proposed treatments, their benefits and risks and, where relevant, the costs involved

n) refuse or withdraw from treatments, tests, scans and investigations without sanction or vilification

o) be told about relevant, appropriate clinical trials available in my current treatment facility and offered a place if I meet the inclusion/exclusion criteria, or be directed to the contact details for a trial taking place elsewhere for which I might be eligible

p) be fully informed of the benefits and risks involved for me and to have sufficient time, without pressure, to consider participation (or not) in a clinical trial, experimental procedures or investigational programs

q) have my trial participation, should I enroll in such a study, acknowledged and appreciated and be advised of the final outcome of the trial

r) regularly scheduled follow-up appointments and appropriate scanning and tests if I have completed treatment for my brain tumour

s) be treated by an expert health care provider for follow-up. If I am a pediatric patient, this will include being treated by an expert health care provider familiar with the late effects of treatment.

6. THE CARE RELATIONSHIP

I shall have the right to:

a) access an up-to-date contact list of neurosurgeons, radiation oncologists, neuro-oncologists, neurologists and other specialists in my area/country, as needed

b) be provided with the name and contact details of a knowledgeable staff member at

my treating facility who may be able to answer urgent questions out of hours and at times other than scheduled consultations

c) express my opinion or complain without fear of retribution if I receive unsatisfactory care at an institution. I shall also have the right to be given information on the means of expressing this opinion/complaint to management level staff and to expect my complaints to be investigated and the findings conveyed to me in a timely and comprehensive manner

d) challenge my doctor's opinion in a respectful manner and expect the same respect in return

7. SUPPORTIVE/PALLIATIVE CARE

I shall have the right to:

a) receive high quality, fully integrated, multidisciplinary early palliative care which encompasses symptom management, pain relief, psychosocial support, rehabilitation and social and spiritual support

b) receive optimal medication to relieve the symptoms and side effects of my brain tumour and its treatments such as pain, nausea, seizures, etc

8. REHABILITATION AND WELL-BEING

I shall have the right to:

a) access rehabilitation programmes (including speech and language therapy, occupational therapy, neuro-psychological therapy and physical therapy) to address cognitive, behavioural and physical deficits resulting from my brain tumour so that I can maximise my independence and recapture my ability to function as normally as possible

b) information about benefits funding (where available) to ease financial burdens

c) access wellbeing programs specific to my situation as a survivor taking into account my particular, individual needs (including family, employment, financial and psycho-social requirements)

9. MEDICAL INFORMATION AND PRIVACY

I shall have the right to:

a) have my brain tumour properly registered in my country's (and international) cancer registration records whether my brain tumour is so-called 'benign', low grade or high grade

b) my own personal physical space and the maintenance of dignity through all tests, investigations, treatments and procedures

c) have conversations with medical and other professionals about my health and wellbeing which remain private between us

d) wear appropriate clothing during treatment and care to protect my privacy and minimise embarrassment

e) keep medical information about myself from being disclosed to other parties without my permission

f) decide with whom, when and where to share information about my health

10. APPROPRIATE END-OF-LIFE OPTIONS AND CARE

I shall have the right to:

a) discuss all available end-of-life care options, or be referred to other doctors who are willing to discuss them with me at any point in my brain tumour journey

b) my primary cause of death being accurately reflected in government records as a brain tumour if such is the case

c) the proper and appropriate quality and level of care that I decide is right for me as I approach the end of my life

d) my dignity, and to compassion and respect from others

e) express my wishes as to my preferred place of death, for example in hospital, at home, in a hospice, etc

f) advance care planning

g) donate any part of my body, including my brain and tumour tissue samples, to research or to refuse to do this

h) make my own end-of-life decisions and for these to be respected as far as they can be within the current laws of the country in which I am receiving treatment and/or care

THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS DRAFTING COMMITTEE:

Kathy Oliver, International Brain Tumour Alliance (IBTA); Gordon Oliver, International Brain Tumour Alliance (IBTA); Barrie Littlefield, (formerly of) Cure Brain Cancer (Australia); Kristina Knight, (formerly of) National Brain Tumor Society (USA); David Arons, National Brain Tumor Society (USA); Danielle Leach, National Brain Tumor Society (USA)

This is Version V.06/2020 of *The Brain Tumour Patients' Charter of Rights*.

APPENDIX
THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

The following organisations* have ratified the Charter and support its aims:

AICSO
Associação de Investigação de Cuidados de Suporte em Oncologia

American Brain Tumor Association®
Providing and pursuing answers®

American childhood CANCER ORGANIZATION

ASIAN SOCIETY FOR NEURO-ONCOLOGY
ASNO

astro brain tumour fund

BANA
British Acoustic Neuroma Association

BNOS
BRITISH NEURO-ONCOLOGY SOCIETY

brainstrust
the brain cancer people

Brain Tumour Action

BRAIN TUMOUR ALLIANCE AUSTRALIA
1800 857 221

Brain Tumour Foundation of India

brain tumour foundation of Pakistan

BRAIN TUMOUR IRELAND

Brain Tumor Network
Guiding Patients. Empowering Care.

BRAIN TUMOUR NORTH WEST

BTRC

Brain Tumour Research

BRAIN TUMOUR SOCIETY (SINGAPORE)

*Organisations listed in alphabetical order

continued ➤

BRAIN TUMOUR SUPPORT
Together WE are Stronger

He waka eke noa
brain tumour support NZ
In it together

BRAINWAVES NI

BTSG Awareness Foundation

CBTA
CYPRUS BRAIN TUMOUR ASSOCIATION

CBTRUS
Central Brain Tumor Registry of the United States

cernfoundation
Collaborative Ependymoma Research Network

中華民國腦瘤腦癌兒童協會
CHILDHOOD BRAIN TUMOR ASSOCIATION OF TAIWAN

Childhood Cancer International

COGNO
COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

EANO
EUROPEAN ASSOCIATION OF NEURO-ONCOLOGY

endbrain cancer
Fueling Research & Clinical Trial Enrollment

EORTC
European Organisation for Research and Treatment of Cancer
The future of cancer therapy

TOGETHER WE THRIVE...
EPIDERMOID BRAIN TUMOR SOCIETY

Fondo Alicia Pueyo

GLIA
CROATIAN BRAIN TUMOR ASSOCIATION

GLIOMA FUNDACJA CENTER

Head for the Cure Foundation

hersentumor contactgroep
hersenletsel.nl

Hjernesvulstforeningen

HJERNETUMORFORENINGEN

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

ILAM The Israeli Brain Cancer Association

ISNO Indian Society of Neuro-Oncology

JACOBS HOPE FOUNDATION

NPO 法人 脳腫瘍ネットワーク JAPAN BRAIN TUMOR ALLIANCE

KARTU LENGVIAU

KORTNEY ROSE FOUNDATION

Levi's Star Children's Brain Tumour Charity

MARK HUGHES FOUNDATION

MPNE

Melanoma Patient Network Europe

MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION, INC

National Brain Tumor Society

niños con cáncer Federación Española de Padres

IHI A RANGI NZ Brain Tumour Trust

Oligocyte un geste, un espoir Vaincre les tumeurs cérébrales

OLIGO NATION UNITING FOR A CURE

Oscar's Angels France

Oscar's Angels Italia

OurBrainBank

continued ➤

小児脳腫瘍連絡会
PBTN
Pediatric Brain Tumor Network Japan

peace of mind
Brain cancer support, here and now.

Pediatric Brain Tumor Foundation

PVW BRAIN TUMOR FOUNDATION

RainBows and Smiles
supporting kidz with cancer

ROBERT CONNOR DAWES
RCD
Foundation
SUPPORTING BRAIN MATTERS

San Diego Brain Tumor FOUNDATION
Supporting the Needs of Patients & Families

SNO
The Society for NeuroOncology

SNOSSA

SOUTHEASTERN BRAIN TUMOR FOUNDATION
SUPPORT • HOPE • COURAGE

Stichting
www.STOPHersentumoren.nl

students SUPPORTING brain tumor RESEARCH

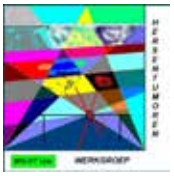
SVENSKA HJÄRNTUMÖR FÖRENINGEN

THE BRAIN TUMOUR CHARITY

the GRAY MATTERS foundation

THE HONG KONG NEURO-ONCOLOGY SOCIETY

The Japan Society for Neuro-Oncology
Since 1980



The Brain Tumour Patients' Charter of Rights
is a living document.
If your organisation would like to support the Charter please contact kathy@theibta.org

If you would like to volunteer to translate *The Brain Tumour Patients' Charter of Rights* into another language, please contact kathy@theibta.org

Guidelines for *Charter* translators can be found at https://theibta.org/charter/

Charter document design:
Edwina Kelly · edwina@edwinakellydesign.co.uk

We have to think of those who succeed

Fátima, 47 years old, lives in Portugal with her mother and one of her sisters. Her sister is her caregiver and support. Fátima was diagnosed with breast cancer with bone metastases in 2016 and in January 2018 was diagnosed with brain metastases. Here are some observations from Fatima as she continues on her journey.

Between the first diagnosis of my breast cancer and until I knew I had brain metastasis, it took two years. At home when I spoke, I noticed I was "dragging" my voice. I didn't have the strength to speak. So I called my doctor, explained that I had no voice, that my voice was "mushy", and that I felt different when walking.

When I found out that I had metastases to the brain, it was like a tumble. I think it was one of the most difficult things to deal with. That was when I felt the lowest, when I said to myself: "My God! What is this?"

I suffer from forgetfulness and have difficulty talking. Sometimes I want to say something, and it doesn't come out. It is not really a lack of memory, because I remember everything, but it's something that has been lost.

Fátima

I don't want to cry… but occasionally I do. During treatments, I felt as everyone else feels: sad. I had no hair. I cried my eyes out. I asked myself, why do I cry? I have to think about overcoming this challenge and not about hair. Hair grows again!

Fear is always there. Sometimes people say "I heard that..", "I read this…", "Everything will be fine…" But it's not. One who has cancer is never at peace. It gives you anxiety. You have to feel your own body, not others'. Everyone goes through this in different ways.

From time to time there is a little headache here and there, but it goes away. But if I do feel a headache, I immediately think of a tumor, right?

I'm recovering. I really like to walk in my local area, which is a pine forest. Reading, walking, having faith are all things that help me deal with the disease. I talk to God a lot, hold on to Him a lot.

Whoever has cancer - cry, but don't be afraid. Because you can also win. There are some who don't, but there are others who do. We have to think of those who succeed. ■

European Cancer Organisation and the EU Health Commissioner

IN January 2020, IBTA Chair Kathy Oliver was privileged to meet with recently appointed EU Commissioner for Health and Food Safety, Stella Kyriakides as part of a delegation from the European Cancer Organisation where Kathy serves as Vice-Chair of the Patient Advisory Committee (PAC). Ms Kryiakides is no stranger to patient advocacy. As a cancer survivor herself and a former Chair of the European Cancer Organisation's Patient Advisory Committee, she has been a tireless campaigner for improved outcomes for cancer patients.

The European Cancer Organisation will be working with Commissioner Kyriakides, its 31 Member Societies and 20 patient advocacy organisations to support the progress of the EU4Health programme (2021 to 2027) which aims to assist recovery of the health sector after the novel coronavirus pandemic passes, help boost strength of health systems for the longer term, and eliminate weak points exposed during the pandemic. ■

European Cancer Organisation representatives meet with the EU Health Commissioner earlier this year (left to right: IBTA Chair Kathy Oliver; EU Health Commissioner Stella Kyriakides; President of the European Cancer Organisation's Board of Directors Dr Matti Aapro; and Mike Morrissey, Chief Executive of the European Cancer Organisation)

Meet The Sontag Foundation's recently-appointed Executive Director, Hilary Keeley

Hilary Keeley was named Executive Director of The Sontag Foundation in January 2020 replacing the Foundation's long-time Executive Director, Kay Verble, who retired at the end of 2019. The Sontag Foundation is a private family foundation, founded in 2002, taking its inspiration from Susan Sontag who was diagnosed with an anaplastic (grade 3) astrocytoma in 1994. The Foundation is one of the largest private funders of brain cancer research in the United States and has invested US $35 million to support this field. To date the Foundation has awarded 51 research grants at 34 institutions in the US and Canada through its annual Distinguished Scientist Award.

Most recently, The Sontag Foundation established a COVID-19 Emergency Patient Assistance Fund to provide financial support to patients diagnosed with a brain tumour or their caregivers who have been impacted by COVID-19. The fund helped eligible patients with the costs of their basic daily needs, including food, rent or mortgage, utility bills, car payments and other transportation expenses, childcare, and temporary lodging for medical appointments. The fund has now closed but during its operation, it provided financial support to nearly 400 brain tumour patients and caregivers who were affected by COVID-19.

Here, Hilary shares some of her thoughts about her new role at The Sontag Foundation.

THE SONTAG FOUNDATION

IBTA: Hilary, what responsibilities come with your new role at The Sontag Foundation?

Hilary Keeley (HK): As the Foundation's second Executive Director, I am entrusted with carrying out the Foundation's mission to passionately support people and organizations who make a significant and continuing impact in the lives of individuals with a major strategic focus on brain cancer research and support for patients with brain cancer. I oversee all of the Foundation's grant programs, including our Distinguished Scientist Award for young career scientists. I serve as a liaison between The Foundation and other local, state, and national organizations, both within the brain tumour community and beyond. I also work closely with our founder and President, Rick Sontag, to look for new opportunities to expand our footprint in meaningful ways.

IBTA: What are your first impressions of the brain tumour arena?

HK: I see tremendous opportunity and hope. I continue to see breakthroughs in the advancement of potential therapeutics and I am encouraged by the discussions to improve the clinical trial process. I see researchers collaborating cross-institution and sharing critical data. From a patient perspective, organizations are supporting the need for survivorship programs and care navigation as essential tools in a patient's care plan. As I continue to spend time with the young career investigators we fund through our Distinguished Scientist Award, I am energized by their desire to make a difference, both at the bedside and in the lab.

Hilary Keeley, Executive Director, The Sontag Foundation

IBTA: What led you to become involved in this field?

My cousin was diagnosed with a brain tumour and unfortunately passed away fairly quickly after diagnosis, leaving behind a wife and two children. I also have a college classmate who was undergoing treatment for a meningioma last year. Both of these experiences illuminated the challenges as well as the progress for patients diagnosed with a brain tumour.

I'm drawn to opportunities to improve access to quality healthcare and to improve health outcomes. My career began as an attorney for the United States Department of Health and Human Services and next as a Senior Health Policy Director and ultimately Acting Chief of Staff for the Indian Health Service, a US $6 billion federal healthcare system servicing American Indians and Alaskan Natives. Through these experiences, I saw first-hand the disparate condition of healthcare within our country and worked to alleviate barriers for patients to access quality health services.

February 2020 - The Sontag Foundation's annual retreat in St Augustine, Florida, for their Distinguished Scientist Award recipients

As Executive Director of The Sontag Foundation, I get to spend every day looking for ways to make a difference for patients impacted by a brain tumour. We have a terrific team and I'm so fortunate to be able to work with Rick Sontag to execute his vision and his legacy, which is simple: finding a cure for brain cancer and improving the lives of patients and their families.

IBTA: Brain tumours are a rare cancer and bring with them some unique challenges. What has struck you so far about these challenges?

HK: The amount of funding going to brain tumour research is small compared to other forms of cancer and the costs of bringing a potential new therapy to market is expensive. This presents additional challenges to move the field forward when the disease is not in the spotlight. Our Foundation began investing in young career scientists with a particular interest in brain tumour research with the goal to keep talented and motivated researchers in field. As a founding member of the Brain Tumour Funder's Collaborative, we work with other funders to support later stage research to continue to help advance treatment options. We are also continuing to look at the life cycle of research from the lab to the bedside to try to identify other pain points so that we can continue to help move research forward.

IBTA: What, to date, gives you the most satisfaction from your work at The Sontag Foundation?

HK: The opportunity to connect with our Distinguished Scientist Award recipients. Our annual retreat in February gave me the chance to meet our grant community and scientific advisors in person. However, through the pandemic, we developed virtual monthly connections with our grantees and advisors, which is only deepening our relationships. I believe the opportunity to work through the challenges of closing and reopening labs, the uncertainty of research funding and personal struggles with school and childcare, will continue to bring our community even closer together in the coming years.

IBTA: What experiences and learnings from previous work positions are you bringing to your role at the Foundation?

HK: My time working for the Indian Health Service taught me to take the time to listen and to try to understand a person's unique journey. There are 574 federally recognized tribes in the United States, each with unique governing structures, cultures, and traditions. While the issues facing the tribes may be similar, the approaches were never one size fits all. I believe this is very similar to some of the challenges facing the brain tumour community. The end goal is the same, but what works for one patient may not work for another just like the treatment that works for one tumour does not necessarily work for another.

IBTA: What impact has COVID-19 had on the work of The Sontag Foundation so far this year?

HK: Financially, we were prepared to weather the storm. In March, we called a staff meeting and sent everyone home to work remotely. The transition was seamless as a result of smart investments in our IT infrastructure. We immediately called our grantees, both current and alumni, and said that we will continue to pay our grants on time and if anyone needs an extension to please call and we will work with you. We announced that we would be moving forward with our 2020 grant awards. We started monthly virtual connections with our grantees to check in and provide them with an opportunity to hear from others ➤

across the country with similar experiences. Probably, the most notable impact was the creation of our COVID-19 Emergency Patient Assistance Fund. Through this initiative we provided a total of $200,000 in grants to almost 400 patients across the United States impacted by COVID-19.

IBTA: What is the role you would like to see The Sontag Foundation playing in the coming years?

HK: We anticipate the financial impacts of COVID-19 will continue well beyond this year. I would like to see The Sontag Foundation continue to build partnerships to make the best use of finite resources. We are working with other organizations to identify the strengths we bring to the brain tumour community and finding ways to work together with a common voice to move the needle and advance critical research.

I would also like to see the Foundation continue to expand the career development resources we provide our grantees. We plan to continue our monthly virtual connections beyond COVID-19 as a way to stay in touch with our grantees between our annual retreats. We are also working on identifying other opportunities to provide our grantees with forums to inspire collaboration and community, both in person and virtually.

IBTA: How do you relax? Do you have a hobby or a sport with which you are involved?

HK: We are fortunate to live in a coastal beach town so I spend a lot of time outside with my husband and two daughters. We look for shells and shark's teeth on the beach, take bike rides, and spend time on the water. I also enjoy traveling and look forward to being able to visit new places again soon.

IBTA: What would be the first three items on your wish list for brain tumour patients and their families?

HK:

(1) The ability to seek care at the right medical facility, with the right medical team, for their specific tumour type, without regard to their ability to pay.

(2) An easy and unencumbered right to try eligible investigational drugs.

(3) Access to unbiased patient navigation services to make sure all brain tumour patients and their families are informed and educated to make the best decisions regarding their care plans. ■

The IBTA's mission is to advocate for the best treatments, information, support and quality of life for brain tumour patients, offering them, their families and caregivers hope - wherever they live in the world.

European Reference Network

European Reference Networks

http://euracan.ern-net.eu

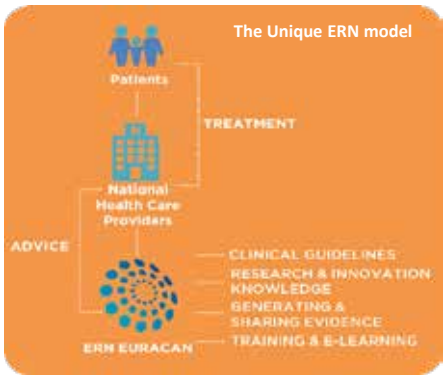
EURACAN

A European Reference network (ERN)
Helping patients with Rare Adult Solid Cancers

The European Reference Networks gathers Health Care Providers with high expertise in the fields of rare or low-prevalence and complex diseases. They are "virtual networks" with experts who discuss the diagnosis and the best possible treatment for patients from all over Europe. **EURACAN is the ERN for Rare Adult Solid Cancers**

Your doctor remains your single point of contact if you are referred to **EURACAN**. Yet, he will have access to the **EURACAN** expertise, can share data, collect the experts' input and discuss it with you at every step of the diagnosis and treatment.

Rare cancers covered by EURACAN



EURACAN specialists do not only discuss individual cases. They also invest in joint research activities, work together on clinical practice guidelines and organise trainings for healthcare professionals.

The patients are the core of the ERNs. Patients' organisations are key partners and played an important role in the creation of the ERNs. They help to work towards better accessibility, clinical excellence and patient outcomes.

Information videos on ERNs for patients and health care professionals - https://europa.eu/!Kj43NU; ; https://europa.eu/!Ff66yQ

Contact: Centre Léon Bérard - muriel.rogasik@lyon.unicancer.fr

Telehealth: What You Need to Know About a Virtual Doctor Visit

Brittany Cordeiro
NCI-CONNECT, Neuro-Oncology Branch, Center for Cancer Research,
National Cancer Institute, National Institutes of Health, United States

Neuro-oncology experts share what telehealth is, the benefits and limitations, how to prepare and what to expect during and after your visit.

The next doctor visits you schedule may be virtual or through telehealth. Telehealth enables your doctor to talk with you and examine you at home through video or telecommunications technologies. Due to the coronavirus disease 2019 (COVID-19) pandemic, hospitals and medical offices across the United States are using telehealth more often now, so patients do not need to travel or make unnecessary trips outside their home.

"Telehealth is a very important and useful tool to deliver virtual health. It enables doctor-patient interaction and enhances patient care, but does not completely replace face-to-face visits," says Javier Gonzalez Alarcon, MD, neuro-oncologist at NCI's Center for Cancer Research, Neuro-Oncology Branch.

According to the National Consortium of Telehealth Resource Centers in the United States, telehealth is a collection of means or methods for enhancing health care, public health and health education delivery and support using telecommunications technologies.

The most conventional type is live video conferencing where both the doctor and patient use a computer or mobile device with video and audio to have a conversation and medical examination. Other telehealth types include recording a video to send to your doctor or for your doctor to remotely monitor conditions like epilepsy or sleep disorders.

"Telehealth visits using video conferencing has emerged as an innovative and practical way to provide care to patients with brain and spine tumors," says Nimish Mohile, MD, neuro-oncologist at Wilmot Cancer Institute, University of Rochester in New York.

Telehealth Benefits

Telehealth has emerged rapidly due to changes in access to health care, especially during the COVID-19 pandemic. Some people with cancer need to limit travel or activities outside of their home since some cancer treatments such as chemotherapy can weaken the immune system and may increase a person's risk for severe illness from COVID-19.

Telehealth's increased uptake at this time is beneficial to patients and health care providers for many reasons. It may be safer or more convenient for patients to be at home or health care providers to be in their office instead of a clinic room during the visit.

During a telehealth visit, neuro-oncologist Dr. Javier Gonzalez Alarcon at the National Cancer Institute's Center for Cancer Research, Neuro-Oncology Branch, in the United States, is able to talk with a patient and review medical records and scans.

It saves money by reducing time and expenses of travel. Not traveling also reduces exposure to other people and places and therefore, can lower the risk of catching COVID-19. Because SARS-CoV-2 (the name of the virus while coronavirus is the name of the disease it causes) is a new virus, anyone who is exposed to it is at risk of becoming infected and developing COVID-19.

Telehealth visits, out of necessity, are also usually less complex – less time and less procedures, examinations, and tests – than in-person visits. Charges associated with the visits may be less than an in-person appointment if you are receiving care in the United States.

Telehealth can increase access to specialists and support services. People with brain and spine tumors often need to see doctors with highly specialised training who are at comprehensive cancer centers either for an initial diagnosis or second opinion. "We encourage people to get a second opinion so they can be educated and feel

A telehealth visit benefit is being able to include additional family and medical providers on a visit. Here, the University of Rochester Medical Center, Wilmot Cancer Institute health care team in New York meets with a patient and his family support.

comfortable with their treatment options," says Sara Hardy, MD, neurologist and radiation oncologist at Wilmot Cancer Institute, University of Rochester in New York.

If people live far away from specialty care centers, with no means, ability or desire to travel (for example, due to the risk of COVID-19), telehealth can provide them with the opportunity to access specialists who otherwise would have been beyond their geographical reach.

Additionally, patients with brain and spine tumors often have significant symptoms that impact their quality of life. "These can include changes in vision, hearing, and cognition, seizures, weakness, and sometimes depression or anxiety. Team members, including physicians, social workers and nutritionists, at tertiary care centers can work with them to help positively impact their symptoms and quality of life," says Dr. Hardy.

Using telehealth, patients can set up visits with specialists or support services when it is convenient for them. Often, patients forgo these services because they do not have time during in-person visits and will not travel again for such services.

Patients may also be able to determine eligibility for a clinical trial through a telehealth visit before traveling to enroll.

Telehealth Limitations

Telehealth limitations include technology barriers. Telehealth visits require video with the exception of counseling or mental health visits. Most medical offices use software or an application to ensure the privacy of the telehealth visit.

This means patients need a computer or mobile phone with video and audio capability and the ability to download and use the necessary software or application for the telehealth visit. For some patients who don't have this technology available, the digital divide may prevent them from accessing telehealth. Yet telehealth can also encompass telephone appointments, which may solve this problem for certain types of remote medical consultations.

"The biggest limitation to telehealth is that we cannot do a conventional physical exam," Dr. Gonzalez says. Doctors cannot check reflexes, hearing, vision, abnormalities in sensations, or assess weaknesses, or feel lymph nodes and areas of swelling.

Prepare for a Telehealth Visit

It is important to prepare for a telehealth visit to optimize the interaction. Your doctor's office may even ask you for some information in advance of your visit. This may include recent MRI scans, tissue samples or medical reports.

Before your visit, use this checklist to prepare:

- Test your equipment. Make sure your video and audio work properly and you download any software in advance and know how to operate it.
- Connect your device to a power source or make sure it is fully charged.
- Use a wired internet connection, if possible.
- Write your doctor's office phone number down in case you lose connection during your telehealth visit.
- Close all unnecessary programs on your device to avoid it running slower and for privacy protection.
- Check with your insurance about coverage for the telehealth visit.
- Find a quiet space with adjustable lighting and room to move. You will most likely have to walk, raise your arms, or perform other movements.
- Make a list of your medications, dosages, and frequency, and also have the medication bottles nearby.
- Make sure your caregiver or a family member can join the visit, too. Like an in-person visit, it can be helpful to have a caregiver's support, a second set of ears, someone to offer other insights, take notes or hold the camera when you perform movements.
- Write down your questions and concerns in advance of the telehealth appointment, such as changes in or new symptoms.

You can also prepare for your visit by checking your own vitals – body temperature, blood pressure, heart rate and weight. Write down the numbers and have them ready to share with your doctor. See this video to learn how to check your own vitals: https://www.youtube.com/watch?v=wvBTGm88evY&feature=youtu.be

During a Telehealth Visit

Understanding what will happen during your telehealth visit can help you prepare and feel at ease. "A telehealth visit is similar to an in-person visit because it is a conversation, an evaluation, and an opportunity to connect," Dr. Mohile says.

Ask if you can record your visit or if your doctor can provide a written summary. Try to stay engaged by treating your telehealth visit the same as an office visit. A typical visit includes talking about your history since your last visit. This includes new or worsening symptoms, other changes, and going through medications. Then, your doctor will perform a medical examination.

The medical examination will include observation – for ➤

example, viewing rashes, infections, surgical scars, and swelling. "We can look at a swollen calf and assess if we think it's a blood clot," Dr. Mohile says.

Your doctor will assess cognition – memory, attention, concentration, and language – through verbal tests like naming and repeating things. Your doctor can assess brain functioning through a neurological examination – viewing eye movements, facial weakness, strength, and walking and coordination.

"We can see whether strength is symmetric across the body, for example, and whether both arms and legs can do similar activities," Dr. Mohile explains.

Your doctor will also be able to share his or her screen and show you imaging results, pathology, and lab reports. He or she can also write out instructions and information about medications, diets, and other treatment recommendations.

Before your appointment ends, make sure you ask all your questions and share your concerns. Make sure you understand the plan or next steps. Will you receive a calendar invitation for your next appointment? Who will arrange your next appointment or MRI? Do you need a referral and if so, what is the process?

Reminders About Telehealth

It is important that you are honest with your doctor during your telehealth visit. If you are having problems with the technology, trouble hearing or seeing the screens, tell your doctor. They can troubleshoot and adjust to improve your experience.

"Patients should also, hopefully, feel comfortable having conversations about intimate or difficult things," Dr. Mohile says. "This can include advanced care planning. However, we understand patient preferences and emotional comfort need to be taken into account. Some people may prefer to discuss these topics face-to-face and that's fine, too."

Telehealth has been especially valuable during the COVID-19 pandemic. "Telehealth has given us the flexibility to have in-depth conversations during our visits to really make connections with patients and their families," Dr. Hardy adds.

Going forward, and when the current pandemic ends, telehealth appointments balanced with face-to-face appointments will most likely continue to accommodate patient preferences. As Dr. Hardy points out, "While telehealth will never completely replace face-to-face visits, it is a very important addition." ■

If you are a neuro-oncology provider, you can watch this webinar to help you learn how to build rapport and connect with patients and their caregivers and learn techniques and strategies that will help you navigate difficult conversations via telehealth. The webinar, titled Patient-Centered Communications via Telehealth in Neuro-Oncology, is hosted by the Society for Neuro-Oncology (SNO) and the Neuro-Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institutes of Health, United States. Visit https://www.soc-neuro-onc.org/ and go to Education then click on SNO Webinar Series.

In conversation with Claire Karekezi, MD - Rwandan neurosurgeon extraordinaire

Dr Claire Karekezi is a Consultant Neurosurgeon based at the Rwanda Military Hospital in Kigali, Rwanda. She has a special interest in neuro-oncology, skull base surgery and endoscopic endonasal surgery. Dr Karekezi is Rwanda's first female neurosurgeon.

IBTA: Claire, it's a great honour and inspiration to have the opportunity to talk to you about your amazing journey to become Rwanda's first female neurosurgeon. First, where did you spend your childhood?
Claire Karekezi (CK): I was born in Butare, Southern Rwanda but I grew up in the capital city Kigali where I carried out my primary and secondary education before going back to Butare for my medical training at the University of Rwanda.

IBTA: Did you come from a family environment that had a connection with medicine or research?
CK: My Dad's uncle was a medical doctor but neither of my parents has a medical background. My Dad is a retired telecommunication engineer; my mum is a retired high school teacher. My uncle, who was also a mathematician, interested me in pursing STEM [science, technology, engineering and mathematics] related fields.

IBTA: What first attracted you to medicine and later, specifically, to brain tumour neurosurgery?
CK: From a young age I knew I wanted to either become a doctor, a pilot or an astronaut. So when I started high school, I told my parents that I wished to pursue STEM related fields but at that time I wasn't completely sure which way I would choose to go. When I finished high school and had to choose a university option, it was at that time clear to me that I wanted to become a medical doctor. I started my medical training in 2002 at the University of Rwanda and finished in March 2009.

During my fifth year of medical school I had a huge opportunity to do an exchange program as a visiting medical student in Sweden and to be in a department of neurosurgery at the Linkoping Teaching Hospital for four weeks. I had planned to be in the department of radiology, but during that summer period most departments did not receive interns. Professor Hillman (head of the neurosurgery department) kindly accepted me.

When I arrived at Linkoping Teaching Hospital, Professor Hillman was on holiday. I roamed around to get used to the new environment.

When he got back, Professor Hillman asked me: "Are you the student from Rwanda?"

I said "Yes."

"Have you been in the operating room (OR)?"

Claire Karekezi is Rwanda's first female neurosurgeon

"Not yet." I replied.

"Come with me." he said.

For the first time, I discovered the beauty of the brain when I attended numerous surgeries performed by Professor Hillman and he let me scrub next to him. This experience became an enormous inspiration that shaped my interest in neurosurgery. I remember speaking with him between surgeries. He said I could make an excellent neurosurgeon. He wrote my first ever recommendation letter for my neurosurgery career. He became my first mentor.

IBTA: What were the challenges you faced in Rwanda to become a consultant neurosurgeon?
CK: Despite insurmountable difficulties to train and practice as a neurosurgeon in most regions of Africa, I knew deep inside me that I would become a neurosurgeon and I did not give up on my dream. Through perseverance, determination and patience while

working as a general practioner (GP) in Kigali I kept looking for training programs abroad that could accept me. It almost looked impossible to me. I remember most people telling me it is hard for a woman wanting that kind of training.

I had heard about the World Federation of Neurosurgical Societies (WFNS) and knew they had training centers and fellowships at various institutions worldwide. The center for Africa was located at The University Mohamed V of Rabat, Morocco and happened to be the very first accredited center by the WFNS to train African neurosurgeons. This was led by Professor Abdeslam El Khamlichi who later became my second mentor.

This revived my hopes for a chance to become a neurosurgeon. I started emailing Professor El Khamlichi non-stop and cc'ing everyone on the WFNS committee. At first, I didn't get a response. And then, the first response I got back from the Professor was that the center was full and not taking new applications. But that didn't stop me; I continued to email him constantly. Finally, in April 2011, I was admitted to the center and was finally given the opportunity to specialize as a neurosurgeon.

I joined the center for a full five-year residency program in neurosurgical surgery. I completed my training in May 2016 and later took my clinical fellowship in neuro-oncology and skull base surgery at the University of Toronto, Canada (2017/2018).

IBTA: When did you realize that your dream of becoming a neurosurgeon was going to come true?

CK: When I was admitted as a neurosurgical resident at the WFNS Rabat training center, I knew at the end of the training I would become a neurosurgeon. I had promised myself to work hard to make it happen

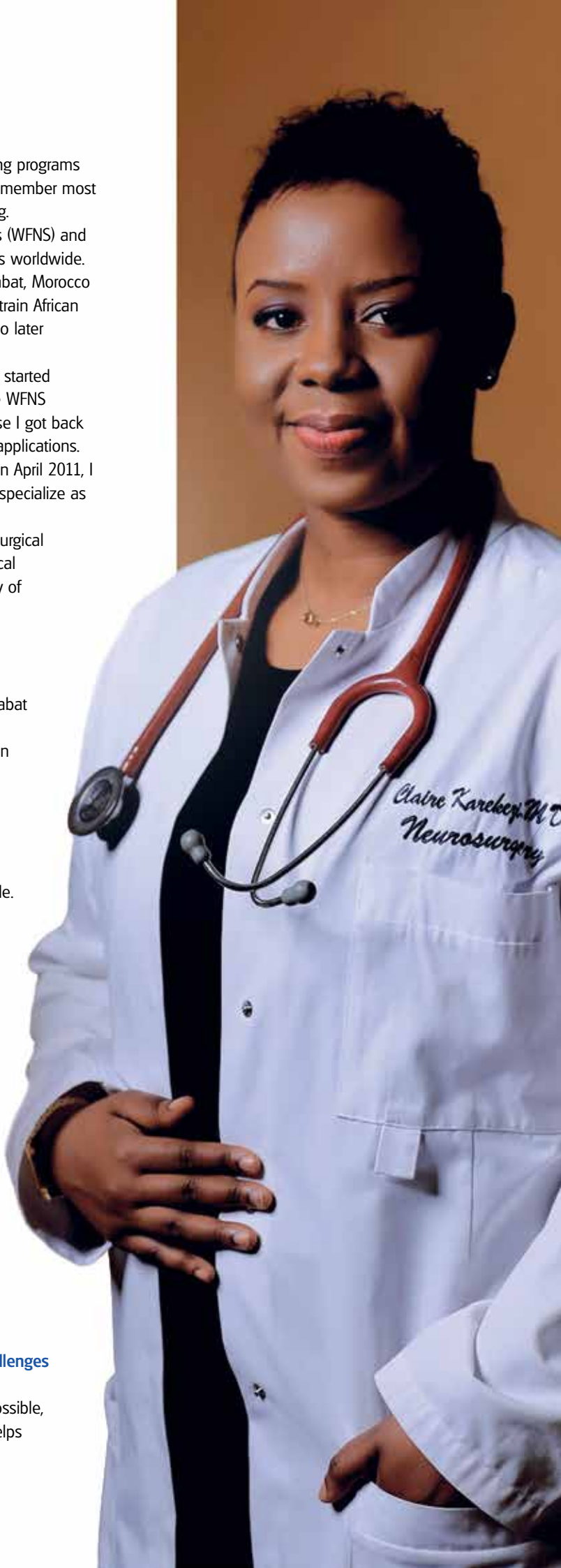
IBTA: What are some of the main challenges of your day-to-day work in Rwanda?

CK: Like other countries in the East-Central Africa region and Sub-Saharan Africa in general, Rwanda suffers from a great shortage of neurosurgeons, with only six neurosurgeons serving 12 million people. When I came back to my country in 2018 after completing my fellowship, I earned a position at the Rwanda Military Hospital in the capital Kigali, where I initiated a neurosurgery department. When I started my practice, I worked alone for one year. Now, I have a second colleague helping me. Transitioning from well-established neurosurgical units with mentors/ supervisors and dedicated teams to a situation where you have to initiate everything from scratch has been one of the most challenging situations I have ever faced.

My beginnings were challenging, from being able to do simple cases to more complex ones, and organizing a team and allocating appropriate surgical instrumentation. The lessons I learned about neurosurgical education and healthcare systems organization during my overseas fellowship have helped me in setting up the new unit. Now the department is up and running. Most cases we see include all kind of trauma, central nervous system infections, congenital anomalies and a lot of brain tumors.

IBTA: How do you cope with the emotional and psychological challenges to you personally arising from your work?

CK: The workload is enormous but I do my best to rest whenever possible, I also get incredible support from my family and friends. All of this helps me a lot in carrying on.



Neurosurgeon Dr Claire Karekezi at work in the operating theatre at the Rwanda Military Hospital in Kigali, Rwanda

IBTA: Do you anticipate any significant breakthroughs in neurosurgery in the next ten years? If so, in what areas?
CK: One of my dreams, ever since I started my neurosurgery path, has been to set up a dedicated neuro-oncology center one day in my country. This is a project I carry in my heart but there are still a lot of challenges I face - like building up my own learning curve and growth as a young neurosurgeon. I also hope to be able to build up a solid team to help me. I am very much interested in neurosurgery academia - it is important for me to transmit what I have learned to the next generation of incoming neurosurgeons. I look forward to this.

IBTA: How has the current COVID-19 epidemic affected your work as a consultant neurosurgeon in Rwanda?
CK: The first days of lockdown were challenging for everyone, especially for brain tumor patients who probably couldn't get to us in time. But those who were really sick got to us regardless and we helped them. Also, initially we reduced our elective surgeries and consultations to contain the virus. Now things are more stable.

IBTA: As Rwanda's first female neurosurgeon, what words of advice would you give to young women contemplating a career in neurosurgery?
CK: Never feel discouraged in embracing any surgical career, especially neurosurgery. Challenges are there but things have evolved and we have more role models and mentors who made it. I would tell them to keep working hard and maintain discipline and GRIT. These things - for sure - do pay off.

IBTA: So far, what has been the most memorable or most satisfying moment of your neurosurgical career?
CK: First of all, being able to finish my training in neurosurgery despite all the incredible challenges facing me to get there.

Then, working in my own country. I feel more useful here. Even if practicing neurosurgery is still challenging, it feels very rewarding when at the end of the day I have treated a patient who goes back home on his/her feet, cured. When I operate on a tumor, it is very heartwarming seeing the patient walk away knowing that I have contributed to treating him/her.

IBTA: What's on your wish-list for brain tumor patients in Rwanda (or, more broadly, Africa)?
CK: At the top of my wish-list would be:

- For patients to get diagnosed on time and get all needed support
- For patients to have access to proper treatment and a multidisciplinary care team
- I also wish to see all the advanced treatments available to the African/Rwandan population

IBTA: How do you relax? Do you play music? Do you have a hobby?
CK: I love traveling and discovering new places. But I also enjoy spending time with friends and family. I also love watching and playing basketball, reading and listening to music.

IBTA: Is there anything else that you would like to add?
CK: Just to say, thank you so much for highlighting our work. We hope for a great collaboration with you in helping brain tumor patients on the African continent. ■

Rights-based advocacy

The IBTA is a strong supporter of rights-based advocacy.

Included in this issue of *Brain Tumour* magazine is the recently launched ***Brain Tumour Patients' Charter of Rights*** which the IBTA proudly co-authored and supports.

PROUD SUPPORTER OF THE
European Code of Cancer Practice

The IBTA is also proud to support the **European Code of Cancer Practice**, a citizen and patient-centred manifesto for the core requirements for good clinical cancer practice, in order to improve outcomes for all of Europe's cancer patients. The Code has been co-produced by a team of cancer patients, patient advocates (including the IBTA's Chair, Kathy Oliver) and cancer healthcare professionals.

Additionally, the IBTA supports the **Glioblastoma Bill of Rights**, a patient-centred call to action. ■

INTERNATIONAL BRAIN TUMOUR ALLIANCE

in association with

NCI CONNECT
Comprehensive Oncology Network Evaluating Rare CNS Tumors
A program of the National Cancer Institute of the National Institutes of Health

REPORT OF THE 4th BIENNIAL WORLD SUMMIT of BRAIN TUMOUR PATIENT ADVOCATES

bridging our communities across the globe…
building progress…building hope

9th to 12th October 2019

The National Institutes of Health (NIH) and the
Hyatt Regency Bethesda Hotel, Bethesda, Maryland, United States

Ninety-seven patient advocates, researchers, healthcare professionals, regulators, representatives of industry and others from 25 countries attended the IBTA's fourth biennial World Summit of Brain Tumour Patient Advocates

Acknowledgements and sponsors

The International Brain Tumour Alliance (IBTA)
is grateful to the following companies for their support.

The IBTA wishes to thank the following who helped make the Fourth Biennial World Summit of Brain Tumour Patient Advocates such a successful event: **the 97 patient advocates, researchers, healthcare professionals, regulators, representatives of industry and others** from 25 countries who attended the IBTA's fourth biennial World Summit of Brain Tumour Patient Advocates at NIH; **Dr Mark Gilbert** (Chief, Neuro-Oncology Branch, NCI, NIH) and **Dr Terri Armstrong** (Deputy Chief, Neuro-Oncology Branch, NCI, NIH) for their generous invitation to have the IBTA's 2019 Summit at the National Institutes of Health; **Kathleen Mercure** (Project Manger, NOB, NCI, NIH) and **Brittany Cordeiro** (Advocacy Liaison and Navigator, NOB, NCI, NIH); the IBTA Senior Advisors for their help and support in organising the Summit (**Jean Arzbaecher, Jenny Baker, Rosemary Cashman, Maureen Daniels, Stuart Farrimond, Anita Granero, Carol Kruchko, Sharon Lamb, Mary Lovely, Mary Ellen Maher, Christine Mungoshi, Sally Payne and Chris Tse**); the Summit **speakers, workshop leaders and Neuro-Oncology Branch (NOB) laboratory guides and researchers; Christine Quah** (Manager, Global Accounts, Helms Briscoe) for organising the Summit accommodation; **EUREST** (NIH Catering Services) and **Kristen Heim** (Hyatt Regency Hotel, Bethesda).

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Variations in spelling: Spelling in this publication varies according to country-specific practices and is thus variable throughout this report. For example, the word "tumor" is spelled as "tumor" in the United States but "tumour" in the United Kingdom and other countries. Sometimes the term "neuro oncology" is expressed without a hyphen and at other times with a hyphen as in "neuro-oncology". To preserve the international nature of this report, the IBTA has decided to vary spellings accordingly.

Day One: Thursday 10 October 2019

National Institutes of Health Bethesda, Maryland Campus

Plenary Session 1

Chair: Kathy Oliver, International Brain Tumour Alliance (UK)

The fourth biennial World Summit of Brain Tumour Patient Advocates got off to a lively start at the National Institutes of Health in Bethesda, Maryland, US.

The fourth biennial World Summit of Brain Tumour Patient Advocates was co-hosted by Dr Mark Gilbert (left) and Dr Terri Armstrong (right) of the Neuro-Oncology Branch of the National Institutes of Health, Bethesda, Maryland, USA. IBTA Chair and Co-Director Kathy Oliver is pictured centre.

Bus transportation from the Summit hotel took Summit participants to the Bethesda campus of the National Institutes of Health.

Welcome Address - Kathy Oliver

IBTA Chair and Co-Director Kathy Oliver welcomed participants from five continents to the World Summit

Welcome Address - Dr Mark Gilbert

Dr Mark Gilbert, Chief of the Neuro-Oncology Branch at the National Institutes of Health in Bethesda, Maryland

THE IBTA 2019 Fourth Biennial World Summit of Brain Tumour Patient Advocates was held at the National Institutes of Health (NIH) in Bethesda, Maryland, United States from 9 to 12 October. The Summit took place in association with NCI-CONNECT, a programme of the National Cancer Institute (NCI) of NIH which focuses on advancing the understanding and treatment of rare central nervous system (CNS) tumours.

Attending the conference this year were 97 patient advocates, researchers, healthcare professionals, regulators, representatives of the pharmaceutical industry and others, representing 25 countries from five continents.

Kathy thanked the NCI-CONNECT team for co-hosting the Summit, paying special mention to Dr Mark Gilbert, Dr Terri Armstrong, Brittany Cordeiro and Kathleen Mercure (all from the NCI) for their efforts in helping to plan and organise the event.

Kathy introduced a highly anticipated programme of presentations, workshops and panel discussions with an overriding focus on what really matters to brain tumour patients and caregivers. She spoke of "the art of brain tumour patient advocacy" and the important role patient advocates play in the broader brain tumour community.

For many attendees, this was their first visit to NIH and there was a palpable air of excitement in being at one of the world's foremost medical research centres. New participants were warmly welcomed and old friendships from past Summits were rekindled. The Summit participants were united by a common aim: "To significantly improve outcomes for brain tumour patients through greater collaboration, greater knowledge and greater hope," which, in fact, is the IBTA's mantra. The stage was set for a memorable conference.

DR Mark Gilbert, Head of the Neuro-Oncology Branch at NCI, NIH, warmly welcomed Summit delegates before presenting an overview of brain tumour treatment and research at the Neuro-Oncology Branch.

Dr Gilbert spoke about the unique challenges faced by those affected by brain tumours. Because brain tumours are rare, there are many challenges associated with them: fewer available treatments, low levels of government funding for research, patient populations widely dispersed thus making accrual of sufficient numbers for clinical trials difficult, and other issues.

Dr Gilbert said: "Brain tumours affect the core of who we are. There can be changes in personality, emotions, functional status and neurologic symptoms. It's often a diagnosis that you will be living with, and requiring follow-up, for the rest of your life. We don't often use the word 'remission' when it comes to brain tumours, we use the term 'no active disease'. So there is a distinct human impact on the patient and family. It's a difficult disease to treat."

Dr Gilbert outlined the challenges of current brain tumour treatments. He said most tumour types are treated with a combination of surgery, radiation and chemotherapy, however infiltrating tumour cells preclude a surgical cure for many people, there is difficulty in delivering treatment to the tumour because of the blood-brain-barrier, and in time, tumour cells become resistant to treatment.

"Many of the big clinical trials to date have been negative," Dr Gilbert said. A major research area at NIH is "Patient Focused Outcome Assessment". The goal is to reach a conclusion on a drug's clinical benefit (the impact of a drug on how patients feel, function or survive) and to describe the benefits and risks in labelling in a way that is balanced and not misleading.

About the National Cancer Institute

Dr Gilbert explained that NIH consists of 27 institutes, of which the National Cancer Institute (NCI) is the largest. NCI supports both extramural (external) research at national medical centres and medical schools, and intramural (internal) research. NCI Center for Cancer Research (CCR) is part of the Intramural Research Program of NIH. It is dedicated to patient-intensive clinical research and to developing new approaches for prevention, diagnosis, and treatment of cancer.

About the Neuro-Oncology Branch

The Neuro-Oncology Branch (NOB) – whose mission statement is "To improve the treatment and outcomes for patients with brain tumors by collaborative research and compassionate care" - is a division within CCR that conducts basic, translational and clinical research on primary brain and spinal cord tumours.

The neuro-oncology clinic is open to any US and international brain tumour patients over age 18. A feature of the clinical care at the NOB is the unique patient review prior to every clinic, involving a multi-disciplinary team discussion of imaging, available molecular findings and symptom reporting. Molecular profiling is routinely performed and prior to a patient's initial visit his/her tumour will also undergo pathology review in a formal session with the NOB Clinical Team.

The NOB has a special interest in rare brain tumours and there has been an increasing number of referrals to them for these.

The clinical research programme at NOB is co-led by Dr Gilbert and Dr Armstrong. Their expanding clinical research portfolio contains both therapeutic and non-therapeutic studies, including the Natural History Study. "Most clinical trials are negative without understanding the reason for failure," said Dr Gilbert. "Outcomes need to improve, we need to do better."

IBTA Senior Advisor Chris Tse (New Zealand) snaps three World Summit participants. Left to right: Brock Greene (OligoNation), the IBTA's Kathy Oliver and Dr Mark Gilbert of NIH

Update on Surgical Approaches to Brain and CNS Tumours

Presenter: Edjah Nduom, MD, Neurosurgeon, Surgical Neurology Branch of the National Institute of Neurological Disorders and Stroke (NINDS), National Institutes of Health (NIH)

Key Points

- In the US, board certification for neurosurgery is subspecialised.
- Frameless stereotactic neuronavigation systems are available at most centres in the US and are coming close to being the standard of care.
- Cortical mapping, sub-cortical mapping and continuous electroencephalogram (EEG) assist the surgeon in preserving key brain functions.
- Technologies such as intraoperative MRI and intraoperative ultrasound can assist the surgeon in dealing with brain shift during surgery.
- Diffusion Tensor Imaging (DTI) Fibre Tracking shows which areas of the brain are connected to which parts of the body.
- Awake craniotomy is the preferred procedure for removing tumours close to eloquent areas of the brain.
- Imaging agents such as 5-ALA assist the surgeon to distinguish between tumour and normal tissue.
- Advances in endoscope technology, exoscopes and new techniques such as BrainPath are providing surgeons with incredible close-up vision and precise operation.
- Surgery is playing an increasingly important role in clinical trials, to investigate whether and how much of a drug is getting past the blood-brain-barrier to the tumour.

Neurosurgeon Dr Edjah Nduom from the National Institutes of Health, Bethesda, Maryland, USA

A comprehensive review of state of-the-art neurosurgical approaches was described by Dr Nduom

DR Edjah Nduom is a neurosurgical oncologist in the Surgical Neurology Branch of the National Institute of Neurological Disorders and Stroke (NINDS) at NIH. He gave delegates an overview of what is new and exciting in the field of neurosurgery. Dr Nduom began by reviewing the standard treatment for glioblastoma, before moving on to the role of surgery in the treatment of brain tumours.

What are the reasons for surgery?

Dr Nduom explained that the main reasons to perform surgery on brain tumours are: to find out what to treat, to cure the disease (for benign lesions), to safely reduce the amount of disease, and for clinical trials. "Neurosurgery can cure some benign tumours completely, while radiation and drugs can be more effective on less disease," said Dr Nduom.

Who should perform surgery on CNS tumours?

Dr Nduom said that the field of neurosurgery in the US has changed and board certification is now divided into subspecialties such as tumour, spine, vascular, trauma/critical care, functional and pediatrics. Even brain tumour surgeons can be sub subspecialised, for example, glioma/intra-axial tumour surgeons, open skull base surgeons, anterior/endoscopic skull base surgeons and spine tumour surgeons.

"It's very rare that a patient shows up in the Emergency Department and immediately needs surgery within 24 hours," said Dr Nduom. "In most cases there is time to match the patient with the right surgeon."

He explained that initial patient management often involves dexamethasone, a corticosteroid (for reducing swelling the brain due to the tumour) and anti-epileptic drugs for patients who have experienced a seizure (there is no good data to support seizure prophylaxis before surgical resection), before referring the patient to a high-volume centre for surgical management.

How is surgery performed on CNS tumours?

Dr Nduom explained: "We aim for maximal safe resection. The patients should be closely the same as they were before they came into the hospital for surgery." New technological advances and techniques are assisting the neurosurgeon in achieving maximum resections and better outcomes.

Frameless stereotactic neuronavigation

Frameless stereotactic neuronavigation uses a set of computer-assisted technologies to guide the neurosurgeon during surgery and can be described as "GPS for the brain". This is now coming close to the standard of care in the United States where it is available at most centres.

Intraoperative Neuromonitoring

Intraoperative neuromonitoring procedures include: cortical mapping, subcortical mapping and continuous EEG. "Neuromonitoring is very personnel heavy but actually not expensive," Dr Nduom remarked.

Intraoperative Imaging

The brain often shifts during surgery. Intraoperative ultrasound and intraoperative MRI create real time images during the surgery, giving the surgeon the most accurate information throughout the procedure. In intraoperative MRI set ups, the neurosurgeon is performing the operation inside the MRI coil. However Dr Nduom said very few centres have intraoperative MRI and his centre uses

it occasionally. Diffusion tensor imaging (DTI) is a non-invasive way of determining fibre tracks in the brain. Dr Nduom said: "DTI fibre tracking can show which areas of the brain are connected to which parts of the body."

Awake Craniotomies

The patient is fully conscious during an awake craniotomy surgical procedure, allowing the neurosurgeon to test the patient's function continuously throughout the operation. It is the preferred technique for removing tumours located close to eloquent regions of the brain, such as the speech area. Dr Nduom said: "Awake craniotomies are sometimes carried out for musicians or singers, and most patients do quite well with it." Awake cortical mapping allows the neurosurgeon to map out the important regions of the brain while the patient is awake.

5-ALA for Resection

5-ALA (5-aminolevulinic acid) is an imaging agent (fluorescing brain tumour cells and turning them bright pink under a special blue light used during surgery) which can assist the surgeon to distinguish between tumour and normal tissue, therefore improving the chances of achieving a more complete resection. It is a pink-coloured fluid which is drunk by the patient prior to surgery. The commercial form in the United States is very expensive, and neurosurgeons need to be certified to use it in surgery, which may be slowing its wide adoption.

Endoscope Technology

Advances in endoscope technology now allow for endoscopic surgery for brain tumour resection and/or biopsy. Endoscopic surgery is a minimally invasive technique which uses a tube with a lens and a light source to target the tumour while minimising the trauma to surrounding tissues. The latest equipment can provide the surgeon with incredible close-up vision and precise operation. Often, endoscopic surgeries are performed through the nasal cavity. External operating telescopes, or exoscopes, equipped with highly manoeuvrable robotic arms, can provide excellent high definition visualisation for the neurosurgeon. BrainPath is a surgical system which utilises a device to create a corridor through folds in the brain to the tumour site, rather than cutting through large portions of the brain to reach the tumour.

Surgery is not enough

Despite these advances in equipment and techniques improving the neurosurgeon's ability to perform safe and effective resections, according to Dr Nduom "surgery is not enough". Aggressive tumours such as glioblastoma still cannot be cured by surgery alone and require multi-modality treatments, including novel treatment approaches such as immunotherapy. For this reason, surgery is playing an increasingly important role in some clinical trials. For example, by obtaining tissue samples before and after treatment with a drug, it is possible to investigate how much of the drug is getting into the tumour tissue target. ■

Update on Radiation Therapy for CNS Tumours

Presenter: Christina Tsien, Medical Director, Johns Hopkins National Proton Center, Washington, D.C.

Key Points

- **Brain metastases require a multi-disciplinary treatment approach which is increasingly more nuanced and individualised.**
- **Stereotactic radiosurgery (SRS) offers an alternative, less toxic option to whole brain radiotherapy for patients with brain metastases.**
- **Frameless SRS Technology with advanced imaging guidance offers better patient comfort and more flexible treatment plans.**
- **Amino acid PET imaging may offer advantages over standard MRI in determining true tumour progression over pseudoprogression.**
- **Hippocampal-sparing, whole-brain radiotherapy is an option for brain metastasis patients with good performance status.**
- **Systemic therapies, including immunotherapies, in combination with radiation may improve outcomes in patients with brain metastases.**
- **Dose escalation using intensity-modulated radiation to areas at highest risk of recurrence may improve survival in patients with primary brain tumours.**
- **Proton therapy may reduce acute and late toxicities for young patients and in low grade tumours with good prognosis.**
- **Delayed radiation effects can impact both the tumour and its microenvironment.**

"BRAIN metastases are the most common tumours we see in the brain," said Dr Christina Tsien.

Dr Tsien chose to highlight CNS metastases in breast cancer to exemplify the challenges in treating metastatic brain tumours. With an overall incidence of 10-16%, breast cancer is the second most common cancer to metastasise to the brain, next to lung cancer. Surgical resection followed by whole brain radiotherapy (WBRT) has historically been the standard of care for these patients. However

Dr Christine Tsien gave a presentation on radiation therapy for brain tumours

Among the topics Dr Christina Tsien addressed in her presentation at the World Summit was proton beam therapy

adverse cognitive side effects from WBRT and other treatment-associated morbidities can have a significant impact on quality of life. Stereotactic radiosurgery (SRS), a non-surgical radiation therapy which delivers precisely-targeted radiation in fewer, high dose treatments, offers a less toxic alternative for these patients.

This was investigated in N107C, a phase III randomised trial comparing post-operative SRS with WBRT in resected metastatic brain disease. Trial investigators concluded that post-operative SRS to the resection bed provides equivalent survival, better preservation of cognitive function and quality of life (QL) and less toxicity than WBRT.

Frameless SRS Technology

Dr Tsien explained that frameless SRS Technology utilises custom-made thermoplastic masks with motion management as a non-invasive, safe and effective alternative to the traditional frame-based technique. Frameless SRS allows for the use of fractionated radiotherapy (where the treatment is split into a number of smaller doses or fractions) because patients are no longer required to have a frame attached to their heads during treatment.

While frameless systems offer better patient comfort and more flexible treatment plans, they require advanced image guidance technologies to replicate the degree of accuracy of the fixed head frames, said Dr Tsien. One such technology is cone-beam computed tomography (CBCT) which uses volumetric (3D) imaging and online adaption with automatic patient correction. The radiation delivery is automatically adapted to the patient's head position from CBCT-stimulating a "virtual 6D couch", ensuring a high degree of accuracy.

Pseudoprogression and Amino Acid PET Imaging

Pseudoprogression is a common radiation treatment effect which mimics tumour growth and can arise several years after treatment with stereotactic radiotherapy (SRS).

Dr Tsien explained that positron-emission tomography (PET) imaging offers advantages over standard MRI in determining true tumour progression from pseudoprogression, however the tracer (special dye that is injected prior to the scan) in the commonly used 18F-FDG PET has high background uptake in normal brain tissue which limits the ability to differentiate between tumour and radiation necrosis. Amino Acid PET measures protein synthesis and amino acid transport, which improves response assessment compared with MRI and FDG PET.

Hippocampal Sparing Whole Brain Radiotherapy

Many patients with brain metastases undergoing whole brain radiotherapy (WBRT), said Dr Tsien, experience a decline in cognitive function following treatment. Cognitive function, and specifically the generation of new memory, is known to be associated with neural stem cells located in the subgranular zone of the hippocampus. Studies have shown that standard WBRT is associated with a decline in verbal recall measure four to six months after treatment and results in reduced quality of life.

Researchers hypothesized that avoiding or reducing the radiation dose to the hippocampus by using an advanced form of WBRT called intensity modulated radiotherapy (IMRT) may help preserve cognitive function and memory areas. A randomized phase III clinical trial, NRG-CC001, comparing memantine (a drug used to treat dementia) and WBRT with or without hippocampal avoidance showed that patients treated with hippocampal sparing WBRT had less neuro-cognitive decline post-treatment. However Dr Tsien said that the results were not as good as hoped, indicating that radiation-induced cognitive impairment is multifaceted and reflects alterations in multiple brain regions, not only the hippocampus.

SRS primes immune response to checkpoint inhibitors

In recent years immune checkpoint inhibitors have provided major treatment advances in certain cancers, such as melanoma. However results of studies using checkpoint inhibitors as monotherapy to treat brain tumours have largely yielded disappointing results. Tumours that do not respond to immune checkpoint inhibition are termed "cold tumours" while those that do respond are termed "hot tumours".

Dr Tsien described a hypothesis that radiation could turn melanoma cells from cold to hot, thereby priming them for treatment

with ipilimumab, an immune checkpoint inhibitor. This, said Dr Tsien, suggests that unirradiated tumour cells do not present a sufficient number of antigens (proteins which can be targeted by T-cells) for ipilimumab to be effective, resulting in immune escape by the tumour. However tumour cells treated with radiation undergo cell death and release increased numbers of novel antigens which can induce a robust immune response to ipilimumab.

Clinical trials combining stereotactic radiosurgery with immunotherapy to treat melanoma brain metastases have produced encouraging results, in terms of tumour response rates, increased survival and clinical benefit.

Updates in Radiotherapy for Primary Brain Tumours Dose Escalation

Moving on to radiotherapy advances in primary brain tumours, Dr Tsien outlined the role of radiotherapy in the current standard of care for glioblastoma multiforme (GBM) adding that "local failure remains predominant" and that there is no standard of care therapy at recurrence.

Looking to improve on the current standard of care, researchers investigated escalating the dose of radiation by using intensity-modulated radiation (IMRT) – an advanced form of radiotherapy designed to conform the radiation dose precisely to the target and limit exposure to healthy tissue. Dr Tsien said that a phase II clinical trial showed that an increased dose was well tolerated and produced a promising overall survival (OS) result of 20.1 months.

The same trial also looked at the use of 11 C methionine PET (MET-PET) imaging, a type of PET scan which uses an amino acid tracer, in predicting patterns of recurrence. They found that MET-PET imaging was able to show areas of increased metabolic uptake (indicated the presence of tumour cells) which extended well beyond the enhancing lesion on standard contrast MRI.

Dr Tsien suggested that the use of PET imaging will sometimes show areas of tumour beyond the margins indicated by standard MRI and these areas can be given escalated radiation doses for improved local control.

Low Grade Glioma: Proton vs IMRT dose distribution

Proton therapy is an advanced form of radiotherapy which uses a high energy proton beam to deliver the radiation dose. Unlike conventional gamma or X-ray beams, which do not stop as they pass through the body, Dr Tsien explained, the depth of proton therapy beams can be controlled. As the charged particles come to a stop, all their energy is deposited within the tumour with little to no exit dose to the surrounding tissues. The combination of advanced imaging techniques and proton therapy offers the prospect of more precise targeting of the tumour and less treatment side effects.

Complex interactions between tumour and microenvironment

Another area of intense research interest, said Dr Tsien, is in the tumour microenvironment - the mix of blood vessels, immune cells, signalling molecules and extracellular matrix proteins that surround the tumour. There is a growing recognition that interactions between tumour cells and immune cells present in the microenvironment, such as tumour-associated macrophages (TAMs), can facilitate proliferation, survival and migration of tumour cells.. Animal studies have indicated that delayed radiation effects on the brain microenvironment may contribute to immunosuppression and subsequent aggressive tumour growth.

Dr Tsien concluded by saying: "The tumour is very smart, always changing. Perhaps we should think differently and look at the microenvironment." ■

Plenary Session 2

Chair: Kathy Oliver, International Brain Tumour Alliance (UK)

Systemic Treatment Approaches and Devices for Brain Tumours

Presenter: Dr Duane A. Mitchell, MD, PhD. Phyllis Kottler Friedman Professor, Lillian S. Wells Department of Neurosurgery. Co-Director, Preston A. Wells, Jr. Center for Brain Tumor Therapy University of Florida, Gainesville, USA

Key Points

- Malignant brain tumours are often highly invasive and require aggressive treatment including surgery, radiation, systemic therapy and tumour treating fields (TTF).
- Temozolomide improves survival in GBM but the main benefit is in patients with a silenced MGMT gene.
- Some brain tumour sub-types can be treated with targeted agents.
- The blood-brain barrier (BBB) can restrict access of many drugs into the brain.
- Tumour treating fields (TTF) is the latest advance in

the treatment of glioblastoma.
- Immunotherapy and viral therapies hold significant potential to improve therapeutic outcomes.
- Combination treatments are a focus for future therapeutic development.

Physician-scientist Dr Duane A Mitchell, one of the speakers at the IBTA World Summit of Brain Tumour Patient Advocates, in conversation with Dr Jing Wu of the National Cancer Institute's Neuro-Oncology Branch (NOB)

Dr Duane Mitchell

DR Mitchell began his presentation with an overview of the most common types of brain tumours. "Malignant brain tumours are often highly invasive and require aggressive treatment including surgery, radiation, systemic therapy and tumour treating fields," he said.

He stressed the importance of systemic therapies to try and achieve long term control of the tumour. Systemic therapy was needed because tumour cells existed in distant parts of the brain, far from the original tumour site. The challenge facing clinicians was how to develop therapies that can reach these distant tumour cells. He explained that the standard therapy included surgery and radiation, chemotherapy, targeted agents, tumour treating fields, and anti-angiogenesis treatment.

Temozolomide improves survival in GBM

Chemotherapy with temozolomide improves survival in GBM, as shown in the pivotal phase III study by Roger Stupp et al. published in 2005 in the New England Journal of Medicine. Median overall survival (mOS) is considered the standard metric for effectiveness, however other measures such as two, three and five-year survival are also significant, according to Dr Mitchell. A significant finding of the Stupp et al study was that the main benefit from temozolomide is experienced in patients with a silenced MGMT gene and MGMT can likely predict the response to temozolomide.

Dr Mitchell explained: "Some sub-types of brain tumours can be treated with targeted agents." He cited the example of subependymal giant cell astrocytoma (SEGA) which responds to a class of targeted agents called mTOR inhibitors. One such agent, everolimus, is approved by the US FDA to treat patients with SEGA who are not candidates for surgical resection.

One obstacle in developing new treatments for brain tumours is the blood-brain-barrier (BBB) which can restrict access for many drugs into the brain, said Dr Mitchell. There is a field of research to develop therapies which disrupt the BBB to overcome this problem.

Tumour Treating Fields

Tumour treating fields (TTF), which use electric fields to interfere with cancerous cell division resulting in cell death, is the latest advance in the treatment of glioblastoma. Electrical fields are generated by a wearable head device attached to a battery pack which delivers currents to electrodes placed on the patient's scalp in a precise array designed to target the location of the tumour.

Anti-angiogenesis (bevacizumab)

Dr Mitchell said that the anti-angiogenesis agent bevacizumab is effective in controlling symptoms such as oedema and radiation necrosis but unfortunately studies have not shown that it extends overall survival in glioblastoma patients. Although bevacizumab's main target is to block vascular endothelial growth factor (VEGF), a protein which helps the tumour grow new blood vessels, it also alters the tumour microenvironment. By modulating drug delivery to the tumour microenvironment, bevacizumab may be effective in combination with other agents, including immunotherapy therapies, according to Dr Mitchell.

The Future of Brain Tumour Treatment

Turning to the future of brain tumour treatment, Dr Mitchell outlined some of the main areas of current research interest: 1) immunotherapy, 2) oncolytic viruses, 3) new targeted agents, 4) new devices, and 5) combination treatments. "Immunotherapy approaches offer significant promise, for example, adoptive transfer of cytotoxic T-cells," said Dr Mitchell.

Neoadjuvant Immunotherapy

One area of promise is neoadjuvant immunotherapy where the patient receives an initial dose of the drug prior to neurosurgery, before resuming immunotherapy treatment after surgery. A randomised study in patients with recurrent glioblastoma showed that patients who received neoadjuvant therapy, with continued adjuvant treatment following surgery, survived longer than patients who only received the surgery plus adjuvant treatment.

ATTAC II Trial

Highlighting the promise of new immunotherapy approaches, Dr Mitchell reported on a patient in the ATTAC II trial, a phase II clinical trial evaluating an autologous, pulsed dendritic cell vaccine in patients with newly diagnosed glioblastoma. The vaccine is produced by removing some of the patient's own white blood cells, maturing them into dendritic cells and training them to target the pp65 viral antigen of cytomegalovirus (CMV) which is expressed in many GBM tumours but not normal brain cells. An example of a responding patient, who had an MGMT-unmethylated midline glioblastoma which was partially resected, shows a complete response after only five administrations of the vaccine. The challenge now is to find out how to identify which patients will respond to this type of treatment. "The mechanisms underlying these results are still unclear", according to Dr Mitchell, "but may include specific inflammatory responses or factors within the tumour microenvironment."

Combination Treatments

Dr Mitchell stressed the importance of a combination approach. There were several opportunities to combine treatments including:

- radiation combined with systemic treatments
- vaccines and adoptive T-cell therapies
- oncolytic viruses
- combinations of new targeted agents (pathway inhibitors)
- new devices, such as TTF in combination with immunotherapy

Update on Neuropathology for Brain and CNS Tumours

Presenter: Ken Aldape, Chief, Laboratory of Pathology, CCR, NCI, NIH

Key Points

- The 2016 updated World Health Organisation (WHO) classification of CNS tumours has sparked a resurgence of interest in brain tumour pathology.
- The integration of molecular pathology into clinical practice has important implications for diagnosis and treatment.
- cIMPACT-NOW Update 2 clarified that the term "diffuse midline glioma, H3 K27M mutant" should only be used to describe tumours that are diffuse (infiltrating), midline, gliomas and H3 K27M-mutant, and should not be applied to other CNS tumours (e.g. ependymomas) that are H3 K27M-mutant.
- For diffuse astrocytic-appearing WHO grade II or III gliomas that are IDH mutated, the loss of ATRX expression and/or strong, diffuse TP53 positivity can be used as surrogates for 1p/19q non-codeletion.
- cIMPACT-NOW Update 3 describes the molecular characteristics of IDH-wildtype diffuse, astrocytic glioma which lack the histological features of glioblastoma but which tend to follow a similar clinical course to a glioblastoma.
- DNA methylation profiling is now an important diagnostic tool which can identify many brain tumour sub-types.

"PATHOLOGISTS are coming back to the forefront, even though our offices are usually located in the basement!", quipped Dr Ken Aldape, in opening his presentation.

Dr Aldape's remark reflects the widespread resurgence of interest in brain tumour pathology since the 2016 updated edition of the "WHO Classification of Tumours of the Central Nervous System", also known as the "2016 WHO Blue Book". This update represents a step change in brain tumour pathology, as it is the first time that molecular parameters have been added to histological classifications of many central nervous system (CNS) tumours.

Diagnosis of brain tumours using the traditional histopathological criteria is fraught with ambiguities, such as inter-observer variability and a lack of correlation between pathology and clinical outcome in certain tumour types, for example, ependymoma and diffuse glioma.

Dr Ken Aldape is Chief of the Laboratory of Pathology at the National Institutes of Health in Bethesda, Maryland and spoke to the World Summit participants about the latest developments in neuro-pathology

The introduction of molecular criteria to provide a more accurate classification system represents a major advance in the field. The integration of molecular pathology into clinical practice has important implications for diagnosis and treatment.

cIMPACT-NOW

The 2016 WHO update is widely regarded as a starting point in the molecular characterisation of brain tumours. The Consortium to Inform Molecular and Practical Approaches to CNS Tumor Taxonomy (cIMPACT-NOW) was established to provide a forum to evaluate and recommend proposed changes to future CNS tumour classifications. Dr Aldape presented an overview of two important updates published by the group to date ("Update 2" and "Update 3").

Update 2: H3 K27M

This update concerned the mutation "H3 K27M" which is found in diffuse midline gliomas and occasionally in other brain tumours. The update clarified that the term "diffuse midline glioma, H3 K27M mutant" should only be used to describe tumours that are diffuse (infiltrating), midline, gliomas and H3 K27M-mutant, and should not be applied to other CNS tumours (e.g. ependymomas) that are H3 K27M-mutant but not diffuse midline gliomas.

Update 2 also addressed the possibility of using surrogate markers for 1p/19q co-deletion, which stands for the combined loss of the short arm chromosome 1 (i.e. 1p) and the long arm of chromosome 19 (i.e. 19q), to determine the classification of WHO grade II and III gliomas. The group concluded that, for diffuse astrocytic-appearing WHO grade II or III gliomas that are IDH mutated, the loss of ATRX expression and/or strong, diffuse TP53 positivity can be used as surrogates for 1p/19q non-codeletion. The use of immunohistochemistry (IHC) testing to determine ATRX and TP53 expression negates the need for 1p/19q testing which will result in faster diagnostic turn-around times.

The use of surrogate markers addresses one of the concerns generated by the WHO 2016 update – whether all institutions globally had the necessary facilities to undertake genetic testing. However, Dr Aldape provided a word of caution regarding surrogate tests: "When can we be comfortable not to do 1p/19q testing, as exceptions can occur."

Update 3: IDH-wildtype Low Grade Gliomas

Update 3 describes the molecular characteristics of IDH-wildtype diffuse, astrocytic gliomas which lack the histological features of glioblastoma but which tend to follow a similar clinical course to a glioblastoma. The three molecular criteria are:

- EGFR amplification

and/or

- Gain of chromosome 7 and loss of chromosome 10 (+7/-10)

and/or

- TERT mutation

The finding of any or all of the above molecular criteria in diffuse and anaplastic astrocytic gliomas without IDH mutation indicates WHO grade IV behaviour and tumours can be referred to as "Diffuse astrocytic glioma, IDH-wildtype, with molecular features of glioblastoma, WHO grade IV". This definition can help inform prognosis and potentially guide treatment options.

Dr Aldape remarked: "The cIMPACT-NOW updates are ongoing, and are important in defining new entities for the next WHO classification." He cited the example of spinal cord ependymoma with MYCN amplification, a rare subtype which features multiple (more than 10) copies of the MYCN gene. Spinal ependymomas are

typically low grade tumours with a relatively favourable prognosis after resection, however the presence of a MYCN amplification suggests a more aggressive phenotype with a worse prognosis.

DNA Methylation Profiling

Dr Aldape introduced the emerging concept of classifying brain tumours based on DNA methylation profiling and explained why this is an important diagnostic tool. He remarked: "Appearances can be deceiving. Global methylation profiling allows us to look underneath the surface."

DNA methylation is an epigenetic modification which plays an important role in gene expression. Tumour DNA is analysed using a methylation array, a laboratory test which quantifies methylation levels along selected parts of the genome, and the results interpreted algorithmically using a "brain tumour methylation classifier". The classifier can identify several brain tumour sub-types according to their distinct methylation profile.

Dr Aldape highlighted some key situations where DNA methylation profiling could be utilised in practice:

- confirming a diagnosis
- identifying a tumour sub-type
- as a quality control function – when the initial diagnosis is incorrect

He cited the example of distinguishing between a glioblastoma multiforme (WHO grade IV) from a pilocytic astrocytoma (WHO grade I) where methylation profiling could provide the answer when histology was unclear. ■

Update on Rehabilitation for Brain Tumour Patients

Presenter: Ilyse Lax, Occupational Therapist and Rehabilitation Consultant, Pencer Brain Tumour Centre, Princess Margaret Cancer Centre, Toronto, Canada; Occupational Therapy & Occupational Science, Faculty of Medicine, University of Toronto

Key Points

- **People with brain tumours have greater distress, lower positive affect and more illness intrusiveness than people living with other cancer types.**
- **People living with brain tumours often present with several complex and heterogeneous functional impairments, some due to the tumour itself but also due to the side effects of treatments.**
- **Traditional inpatient and ambulatory rehabilitation programmes are effective and the functional gains are comparable to other acquired brain injury (ABI) populations, however few patients receive this care.**
- **Brain tumours are an evolving condition where the patient's needs change as the disease progresses, which requires an Adaptive Rehabilitation Framework.**
- **The three features of the Adaptive Rehabilitation Framework are: individualised approach, meaningful intervention, and delivered at the right time.**

From Traditional to an Adaptive Rehabilitation Framework

Ilyse Lax is in the business of enhancing the quality of life of brain tumour patients, or simply, "helping people live better". In her presentation at the IBTA Summit, she urged delegates to advocate for an adaptive rehabilitation approach for their patients back in their home setting.

Brain tumour patients comprise a unique population. People with brain tumours have greater distress, lower positive affect and more illness intrusiveness than people living with other cancer types. Positive affect refers to the extent to which an individual subjectively experiences positive moods such as joy, interest, and alertness. The concept of illness intrusiveness represents the illness-induced disruptions to lifestyle, activities, and interests that can compromise psychosocial well-being and contribute to emotional distress. Studies have shown that the high levels of functional impairment experienced by brain tumour patients translates to "loss of participation in valued activities and life roles".

Ilyse explained that to enhance quality of life we need an

"People with brain tumours have greater distress, lower positive affect and more illness intrusiveness than people living with other cancer types," said Ilyse Lax, occupational therapist from Toronto, Canada

Ilyse Lax speaking about quality of life

approach that is both effective and meaningful to the person with whom we're working.

She described three reasons why it is difficult to establish a standard framework for all brain tumour patients: 1) complexity - due to the heterogeneous constellations of functional impairment experienced by patients; 2) traditional models - historically, very few patients receive adequate rehabilitation care due to a lack of resources and isolation between treatment teams; and 3) evolving condition - things change over time; remediation cannot be the exclusive rehabilitation focus.

Challenge 1: Complexity

People living with brain tumours often present with several complex and heterogeneous functional impairments, some due to the tumour itself but also the side effects of treatments. Common among these are: cognitive deficits, fatigue and weakness. Ilyse said that studies show over 75% of brain tumour patients experience three or more concurrent functional deficits – each person with a different constellation.

Challenge 2: Traditional Models of Care

Traditional inpatient and ambulatory rehabilitation programmes are effective and the functional gains are comparable to other ABI (acquired brain injury) populations, for example, stroke. However, few patients receive this care due to: a lack of resources (particularly in certain geographical areas); absence of rehabilitation as a component of a multidisciplinary care; and isolation among various treating teams.

Challenge 3: Evolving Condition

In an acute event such as a stroke, restoration of functioning is the focus and the traditional rehabilitation trajectory is a steady, upward curve representing gradual recovery of function. However, for those living with an aggressive brain tumour, the curve represents more of a "bumpy road". Evidence-based practice, said Ilyse, calls for services that can react quickly and then continue to provide input as the disease progresses and patients' needs change. Rather than exclusively focusing on remediation, there needs to be consideration for prevention of further functional decline, compensation for difficulties and assistance.

What is the Adaptive Approach?

The adaptive rehabilitation framework: 1) uses an individualised approach; 2) is meaningful to the individual; and 3) delivers the right care at the right time.

Individualised Approach

Exploring the individual's concerns impacting on their quality of life is where this approach begins. "I want to be able to…" statements describe a breakdown in the usual interaction the person has between themselves and activity and the environment so that there is now an unsatisfactory outcome.

Ilyse used the example of "Bob". Bob is living with a glioblastoma. As he undergoes treatment, he finds that his physical skills are not quite what they were before. He has slight hemiparesis (one sided weakness) and balance issues. Bob says: "I want to be able to ride a mountain bike."

Meaningful

Next, Ilyse said that to understand what's meaningful to Bob, we need to explore his core values. When asked about what he values most about mountain biking, it was not the environment, getting away from the city or connecting with nature, as one may assume. It turns out that Bob has competed in mountain biking races all over the world for the past 15 years with his son, and since he stopped biking, he has felt more distant from his son.

Right Care, Right Time

In identifying opportunities for intervention, there is a need to target areas that are REALISTIC and in one's CONTROL. Opportunities for intervention may exist at the level of the person, environment or activity.

- **When intervening at the level of the person, rehabilitation tackles challenges in physical, cognitive, psychosocial or perceptual functioning - for example, strengthening exercises when there is a physical weakness.**
- **At the level of the activity, adaptations can be made to suit the person's unique skills/abilities at that point in time. A basic example of this would be sitting on the edge of the bed to put on a pair of trousers when someone is experiencing balance issues.**

■ **At the level of the environment, things can be added, taken away or completely changed to suit the person's abilities. A good example of environmental adaptation is putting a bench in the bathtub or shower to enable the person to sit down.**

In the case of her example of Bob, Ilyse explained that it was unrealistic to restore sufficient balance and strength so that he could go back to mountain biking in the way Bob previously engaged in this activity. So the focus shifted to adapting the activity and the environment, and coming up with a realistic plan that was in Bob's control. Bob and his son set up stationary bikes with race simulators at home and they were able to get back to riding together.

Ilyse concluded her presentation by sharing a digital resource library at bit.ly/RehabLibrary and a standardised assessment which can be used to guide an Adaptive Rehabilitation Framework, the Canadian Occupational Performance Measure (COPM), at http://www.thecopm.ca/about/ ■

Update on NCI-CONNECT

Presenters: Dr Mark Gilbert, Co-Lead NCI-CONNECT and Dr Terri S Armstrong, Co-Lead NCI-CONNECT

NCI-CONNECT is the National Cancer Institute's special programme for rare brain and spine tumours. Dr Mark Gilbert is one of the co-leaders of the programme.

Dr Terri Armstrong is co-leader of the NCI-CONNECT programme

DR Gilbert explained that patients with rare CNS tumours face a number of challenges over and above those patients with more common tumours - for example, delays in diagnosis, lack of a standard of care, limited social and advocacy support, and a lack of clinical trials.

He added that there are also challenges for researchers in the field of rare CNS tumours, including: designing trials for small populations; a limited range of models for developing therapies; slow trial recruitment and difficulties in attracting research funding.

What is NCI-CONNECT?

Recognising this unmet need, NCI-CONNECT - Comprehensive Oncology Network Evaluating Rare CNS Tumors - was established in 2017 to improve outcomes for patients with rare adult CNS tumours.

NCI-CONNECT's mission is "To advance our understanding of adult rare central nervous system cancers by establishing and fostering patient-advocacy-provider partnerships and networks to improve approaches to care and treatment."

NCI-CONNECT is funded under the Beau Biden Cancer Moonshot Program, also known as the National Cancer Moonshot. It is part of the Rare Tumor Patient Engagement Network (RTPEN) and is managed at the National Institutes of Health, National Cancer Institute Center for Cancer Research, Neuro-Oncology Branch.

Goals of NCI-CONNECT

The programme has three primary goals:

1. Develop an infrastructure across a network of national and international sites to study select adult rare CNS tumours
2. Collect, analyse and share data to promote discovery and improve understanding of select adult rare CNS tumours
3. Use the network to facilitate the translation of discoveries into new therapies and methods to improve adult patient outcomes

NCI-CONNECT is starting with 12 tumour types, each with less than 2,000 people diagnosed each year in the United States. The most common tumours covered in the programme are oligodendroglioma/anaplastic oligodendroglioma and ependymoma. The full list of tumour types currently covered by NCI-CONNECT is: ATRT, choroid plexus tumors, diffuse midline gliomas, ependymoma, gliomatosis cerebri, gliosarcoma, medulloblastoma, meningioma (high grade), oligodendroglioma, pineal region tumors, PXA / APXA, PNET.

Dr Gilbert stressed that engaging the patient is the most important aspect of the project. Patients can connect with the programme in

different ways, including: 1) participating in an online survey - "Outcomes and Risk Project for Patients with Adult Rare CNS Cancers"; 2) undergoing a clinical assessment at the NIH – "Evaluation of the Natural History and Specimen Banking for Adult Patients with CNS Cancers"; and 3) treatment trials – disease specific trials and basket trials.

Benefits to patients

Following Dr Gilbert's presentation, Dr Terri Armstrong provided more detail about the NCI-CONNECT programme and specifically what benefits it provides to patients and caregivers. Dr Armstrong explained: "The NCI-CONNECT clinic brings together adult patients with the same rare brain or spine tumour and their caregivers to receive special services."

The first step is to review the diagnosis. The NCI-CONNECT team provides extensive molecular testing on tumour tissue to confirm the tumour type and to look for any genetic features that might help inform or guide treatment. This step is important to confirm the patient's diagnosis and ensure they receive the most appropriate treatment.

This is followed by consultations with the expert healthcare team, including: a health and wellness counsellor to learn coping and wellness techniques; a genetic counsellor to understand the family history and look at risk factors for developing cancer; and a meeting to discuss treatment and clinical trial options.

The CARES group

The CARES (Coping, Advocacy, Relationships, Education, Support) Group offers the patient and their loved ones an opportunity to learn coping strategies from a health and wellness expert during their clinic visit. Patients and caregivers receive practical advice and educational resources designed to help them continue to live fully and improve their quality of life. Each week, patients with the same tumour type are brought together in the clinic to meet each other and share tips and experiences. For some, this is the first time they have had the opportunity to meet someone with the same type of brain tumour.

International patients

The NCI-CONNECT programme is open to international patients. For international patients coming to NIH for a consultation, the local treating physician in the home country is required to refer the patient for an appointment, so that the teams can work together to provide the best treatment possible. Participants can share their experiences by submitting their stories to be posted on the NCI-CONNECT website.

Natural history study

Another important part of the research being undertaken by the NCI Neuro-Oncology Branch is the Natural History Study. This study enrols all patients undergoing longitudinal follow-up (being monitored over time) at NIH. It opened in October 2016 and currently has over 500 patients actively enrolled. By monitoring these patients closely over the course of their disease, the Natural History Study provides important information about the causes, risk factors, range of symptoms, genetic alterations, and clinical progression and outcomes. Using validated patient-reported-outcome measures, patients are able to describe what it feels like to live with a brain tumour and undergo treatments for it.

NCI-CONNECT hosts a number of meetings and workshops throughout the year to bring together leaders in clinical care, basic science and clinical research, as well as patient advocacy partners. The meetings aim to foster collaboration and advance research into better treatments for people with rare CNS tumours. The participation of brain tumour patient advocates ensures that the patient perspective is fully integrated into the process. ■

Ask The Expert Session

An expert panel on the first morning of the IBTA World Summit answered questions from the audience on all facets of brain tumour treatment

Dr Duane Mitchell responds to a question from the World Summit audience

Expert panelist Ilyse Lax answers a question about quality of life and rehabilitation of brain tumour patients

THE first morning's plenary sessions at the IBTA Summit were concluded by an "Ask The Expert" session, featuring a panel of all the morning's plenary speakers. The floor was opened up to delegates for questions to the panel.

Helen Bulbeck of the UK-based charity brainstrust

Helen Bulbeck (brainstrust UK) asked: "When a GBM recurs, what is the preferred treatment pathway?"

Dr Christina Tsien replied that it is important to personalise the treatment because a recurrent tumour is not the same as the initial tumour. Obtaining the tissue and understanding the molecular profile can help direct the treatment approach. Currently there is no standard of care for recurrent GBM so clinical trials are important to help develop new treatments. New immunotherapy treatments are being investigated and re-irradiation might be beneficial in some cases. However, involvement in clinical trials is vital.

Dr Mark Gilbert added that in 10-20% of cases it is not tumour recurrence, it just looks like it (ie pseudo-progression). He stressed that it is very important not to make assumptions. He recommended biopsy or surgical resection at a recognised centre of excellence to confirm if there is tumour recurrence. Resection is a more comprehensive approach, and is also important to obtain molecular pathology.

Dr Edjah Nduom agreed, adding that sampling from various parts of the tumour tissue is important so that the tumour can be better understood and the patient effectively matched to available clinical trials.

Dr Terri Armstrong added that things need to be done differently to increase clinical trial participation rates. More local trials, better transportation options and less stringent eligibility criteria should all be considered to boost trial accrual. Dr Armstrong noted that a recent study was published which addressed this very problem. The paper "Barriers to accrual and enrolment in brain tumor trials", co-authored by IBTA chair, Kathy Oliver, can be accessed from https://academic.oup.com/neuro-oncology/article/21/9/1100/5513026

Brock Greene of OligoNation (USA) poses a question to the expert panel

Brock Greene (OligoNation, US) asked: "It seems that combination trials, in particular involving immunotherapies, are the way forward. Yet we don't hear much about combination trials. Why is it so difficult to put together combination clinical trials?"
Dr Duane Mitchell replied that it was a slow process to evaluate safety and treatment effects of single agents before they could be considered for combination trials and it will take a lot of work to speed up the process. In terms of safety profiles, traditionally single agents have been investigated for safety and toxicity first, but that is now changing. One way to speed up the process is to test the combination first, before the single agents have been evaluated. Combining agents from different pharmaceutical companies has been problematic but now companies are becoming more collaborative. Regulations and priorities also play a role in slowing down the process.

Jessica Morris, founder of Our Brain Bank

Jessica Morris (Our Brain Bank, US) asked: "What is the relationship between finding successful treatments for brain tumours, and finding solutions for other cancers? Because brain tumours represent a relatively small population, it is difficult to raise funds and advocacy. When we find answers to brain cancer, will that provide hope for cancers overall?"
Dr Mark Gilbert: "In the context of rare diseases, many of the seminal discoveries, such as oncogenes, have been discovered in that very context, for example, retinoblastoma. Another example is the fusion of chromosomes in ependymoma, which has led to the role of chromosomes and chromosome stability being increasingly recognised in cancer generally. There is a litany of examples where brain tumours have led to seminal discoveries. In examining challenges regarding drug delivery, we are doing some important things, not only for the brain tumour world but outside the brain tumour field."
Dr Terri Armstrong added that research funding and issues such as rehabilitation are important to cancer in general and not just isolated to brain tumours. The problems are not limited to treatment issues only, but also to advocacy.
Dr Edjah Nduom noted that a significant number of breast cancer patients will become brain tumour patients through metastatic disease. Finding solutions to crossing the blood-brain-barrier, and other challenges in brain metastases, will inform other cancers. Dr Nduom also added that it was important for patient advocates to "get out there and tell their stories".

Ilyse Lax added that supportive care and rehabilitation were approaches already well established in the breast cancer world. She suggested that it would be useful to take a look at what is working in other neurological conditions. Perhaps disease burden in function, as opposed to population incidence, is also worthy of investigation.
Dr Christina Tsien noted that there were already some synergies between primary brain tumour research and brain metastases, for example, in leptomeningeal spread.
Nicole Wallmarth (American Brain Tumor Association, US) had a question for Dr Ken Aldape: "What is your recommendation for educating patients about brain tumour pathology? Should we be keeping up with the cIMPACT-NOW updates or just wait for the next WHO classification update?"
Dr Ken Aldape replied: "I'm a strong advocate for the latest WHO classification." He added that there can be a lag with the healthcare payers, as the new diagnostic tests are more expensive. Patients should be encouraged to ask for a detailed pathological diagnosis from their doctors which is in line with the standards defined in the new classification.

IBTA Chair and Co-Director Kathy Oliver asks neuro-pathologist Dr Ken Aldape a question in the expert panel session

Neurosurgeon Dr. Nitin Garg represented the Brain Tumour Support Group and Awareness Foundation in Bhopal, India and raised a question about the affordability of molecular testing in developing countries

Kathy Oliver (IBTA, UK) asked Dr Aldape: "Should pathologists meet face-to-face with patients to help explain the pathology of their brain tumour in more detail?" Dr Aldape replied: "I think that's a great idea."
Dr Nitin Garg (Brain Tumour Support Group and Awareness Foundation, Bhopal, India) said that there is now an overwhelming number of molecular tests which are important and low-income countries don't have the resources to pay for these. In India they have come up with their own set of diagnostic tests. For example, they are using ATRX as a surrogate marker for 1p/19q codeletion. Dr Aldape said that the affordability of tests in different countries was discussed in the context of the WHO classification.
Delores Kannas (End Brain Cancer Initiative, US) asked if the panel had heard of the Strata study which looked at the large-scale integration of Next Generation Sequencing (NGS) in patients with solid tumours and how this impacted on treatment costs.
Dr Mark Gilbert said that he had not heard of that particular study but suggested that having a precise (molecular) diagnosis to guide

Delores Kannas, RN MSN MHA, Clinical Research Nurse & Patient Navigator at the End Brain Cancer Initiative in the USA

Anita Granero of Oscar's Angels France and Oscar's Angels Italia

Rosemary Cashman is an IBTA Senior Advisor and a Nurse Practitioner at the BC Cancer Agency in Vancouver, British Columbia, Canada.

therapy options will actually save money. He said: "Overall, the cost of molecular testing is a drop in the bucket." Dr Gilbert commented that: "Payers don't hesitate when spending $1,500 on a brain MRI but payers will question spending $2,000 on getting a precise diagnosis via molecular testing"

Anita Granero (Oscar's Angels, France and Italy) asked: "Does the NIH run a pediatric programme? Do you communicate with others in the pediatric field?"

Dr Gilbert replied: "We are in the process of revamping our pediatric activities and increasingly having contact with other groups". He added that the diseases are on a spectrum, as there are some adults with pediatric diseases and vice versa. There are some joint clinical trials and there is huge collaboration in specific disease areas, for example, diffuse midline gliomas. "Increasingly we're going to work together," said Dr Gilbert.

Rosemary Cashman (BC Cancer, Canada) asked: "One of the challenges related to access to treatment is the cost of new therapies. Can you see a remedy to this problem?"

Dr Armstrong replied that this was a really important question which reaches outside of the brain tumour world as well.

Jelle de Vries (hersenletsel.nl, The Netherlands) asked Dr Aldape: "What about patients diagnosed some time ago, how do we deal with them [in terms of molecular analyses]?"

Dr Aldape replied that molecular testing can be important in remedying an incomplete diagnosis, for example, IDH mutation, 1p/19q codeletion, or BRAF alteration. Testing needs to be done in conjunction with the clinician, however currently there is no standard procedure for retrospectively profiling a tumour. Dr Gilbert added that, as a treating neuro-oncologist, he would always want to have the molecular diagnosis in a recurring tumour.

Plenary Session 3

Co-chairs: Petra Hoogendoorn, Founder/Director, Goings On (the Netherlands) and Laure-line Gatellier, President, Japan Brain Tumour Alliance (Japan)

Quality of Life – Enhancing Our Understanding of the Impact of CNS Cancer and Its Treatment

Presenter: Dr Terri Armstrong, Senior Investigator and Deputy Branch Chief, Neuro-Oncology Branch, Center for Cancer Research, NCI

Key Points

- Primary brain tumours are rare and associated with significant mortality and morbidity, however there are survivors, with nearly 700,000 people in the United States living with a diagnosis of a primary brain tumour.
- The biological and physiological effects of the disease ("symptom burden") have a significant influence on overall quality of life (QoL).
- Caring for the caregivers of brain tumour patients is an area of high unmet need.
- Brain tumour patients want treatments to alleviate symptoms and improve QoL, as well as extend survival.
- A collaborative working group is defining the core QoL constructs to be measured in brain tumour clinical trials and ongoing patient care.

■ The Natural History Study is an ideal vehicle to monitor survivorship, an important area of brain tumour research.

■ The increased knowledge and understanding of the issues impacting brain tumour patients' QoL is facilitating the development of practical interventions to improve care.

Dr Terri Armstrong of the Neuro-Oncology Branch, Center for Cancer Research, NCI presented on quality of life issues for brain tumour patients.

The co-chairs of Plenary Session 3 were Laureline Gatellier (left) of the Japan Brain Tumour Alliance (JBTA) and Petra Hoogendorn (right) of Goings On in The Netherlands

DR Armstrong began her presentation by describing her personal experiences in dealing with cancer and how the death of several close family members, including her mother to lymphoma and a cousin to a glioblastoma, served as the inspiration for her career in oncology nursing.

"Primary brain tumours are rare and associated with significant mortality and morbidity," said Dr Armstrong. "However there are survivors, with nearly 700,000 people in the United States living with a diagnosis of a primary brain tumour."

She said that many factors impacted a brain tumour patient's quality of life (QoL) including health, environmental quality, financial conditions, social support, cultural factors, leisure activities, health and social services, life satisfaction, social interactions and functional abilities.

The biological and physiological effects of the disease, ("symptom burden"), have an important influence on the patient's overall QoL. Recent studies in brain tumour populations show that 50% of patients report at least ten concurrent symptoms and 40% report at least three symptoms rated as 'moderate to severe'. However other factors such as the inability to go back to work, inability to perform usual activities, and the significant burden on the caregiver also have a high impact on QoL.

Dr Armstrong said that caring for the caregivers of brain tumour patients is also an area of high unmet need. Family caregivers provide extraordinary, uncompensated care involving significant amounts of time and energy for months or years, requiring the performance of tasks that are often physically, emotionally, socially or financially demanding. Caregivers are constantly challenged to solve problems and make decisions as the care needs of the patient change, yet they feel untrained and unprepared as they struggle to adjust to new roles and responsibilities.

Integrating QoL parameters into drug development

Results from a survey conducted by the Jumpstarting Brain Tumor Drug Development Coalition (US) showed that patients thought it important for brain tumour treatments to alleviate symptoms and improve QoL, as well as extend survival. To ensure that QoL parameters are integrated into the drug development process, it is first necessary to establish and define the core constructs to be measured in brain tumour clinical trials and ongoing patient care. A collaborative working group involving the National Cancer Institute (NCI), Response Assessment in Neuro-Oncology (RANO), Food and Drug Administration (FDA), European Medicines Agency (EMA), and others, including advocacy groups, has identified the following constructs:

Symptoms

- **Difficulty communicating** – subjective report of difficulty with the ability to express oneself in speech or writing or understand speech
- **Pain** – an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage
- **Perceived cognition** – subjective alteration in cognitive processes including executive function, memory or concentration
- **Seizures** – a physical convulsion, minor physical signs, thought disturbances, or a combination of symptoms that is brief and often self-limited resulting from abnormal electrical activity in the brain
- **Treatment Associated Symptoms** – identified treatment-associated toxicities which can only be measured by self-report

Functions

- **Physical functioning** (including weakness/walking) – the ability to perform daily activities that require physical effort and should include walking or apparent weakness
- **Role Functioning** – the ability to work and carry out or participate in leisure or social activities

We can learn from research undertaken in other cancers. A study at Memorial Sloan Kettering in patients with metastatic solid tumours showed that overall survival was extended for people who monitored their symptoms using an online tool. Those monitoring their symptoms also had less admissions to hospital and stayed on chemotherapy treatment longer than patients receiving standard care.

The Natural History Study

Natural history studies are important in understanding the disease trajectory of CNS tumours. The NCI Neuro-Oncology Branch (NOB) "Natural History Study, Evaluation of the Natural History of and Specimen Banking for Patients with Tumors of the Central Nervous System", includes all brain tumour patients undergoing longitudinal follow-up (ie. follow up over a period of time) at NIH, and has enrolled over 650 patients since opening in October 2016. The study combines clinical data, germline DNA analysis and tumour DNA methylation/mutation profiling with patient reported outcomes (PROs) through each stage of the disease.

Data generated by the Natural History Study can help identify patterns in future areas of research, for example, perception of body image, meaning in life, the effect of steroids, and the effect of disturbed sleep. The study has shown that around 30% of brain tumour patients suffer from moderate to severe sleep disturbance and that these patients are at higher risk of impaired cognitive function.

The Natural History study is also an ideal vehicle to monitor survivorship, an important area of brain tumour research. In a group of long-term survivors, defined as patients living longer than five years from diagnosis, 20% were found to suffer symptoms of depression or anxiety. Research into how to identify which patients are at increased risk of emotional distress is ongoing.

The increased knowledge and understanding of the issues impacting brain tumour patients' quality of life is facilitating the development of practical interventions to improve care. For example, new information technologies have the potential to facilitate symptom management and data collection. NCI is

developing an interactive web portal, NCI-SCOUT, which allows patients to report their symptoms online, and a mobile app designed to facilitate symptom tracking and reporting.
Another example is the use of wearable devices, such as Virtual Reality (VR) headsets, to reduce "SCANxiety", the term used to describe the feelings of anxiety many patients experience before or after undergoing a scan.

Dr Armstrong concluded her presentation with some "lessons from the playing field" – practical tips for patients undergoing treatment.

- **"Knowledge is Power"**
  - The more you know, learn and understand about your tumour, your treatment or your recovery, the higher your confidence. Patients will consistently find greater satisfaction in outcomes when they are prepared with facts. "It helps you gain control," said Dr Armstrong.
- **"Join a support group or find your own support network"**
- **"You are your best advocate"**
  - You are the gatekeeper and keymaster, which is for the best because who better to entrust your care to than yourself?
- **"A handful of patience is worth more than a bushel of brains"**
  - Understand that things will not happen as quickly as you hope, need or want.
- **"Two is greater than one"**
  - Try to always take a second set of ears to medical appointments
- **"Different does not equate to worse"**
  - Yes life is decidedly different. Not worse – just different. ■

Patient Reported Outcomes - Asking the Right Questions and Communicating the Answers

Presenter: Dr Paul Kluetz, Deputy Director, Oncology Center of Excellence, US FDA

Key Points

- The FDA's Patient Focused Drug Development (PFDD) programme looks at measurement of clinical outcomes and making clinical trials more patient friendly.
- Legislation such as the 21st Century Cures Act in the United States asks the FDA to review and communicate patient experience data as part of their regulatory assessments.

- Electronic capture of patient data leads to increased efficiencies in clinical trials and a future pipeline of structured real world patient data.
- Patients want more rigorous information on the effect of cancer drugs on quality of life, over and above the traditional endpoints of safety and efficacy.
- Core clinical outcomes include disease symptoms, symptomatic adverse events, physical function, and ability to work/perform leisure activities.

Dr Paul Kluetz of the Federal Drug Administration (FDA) in the USA

Dr Kluetz said: "The use of wearable devices and sensors to capture patient data is another area of promising research."

Dr Paul Kluetz is a medical oncologist and deputy director of the FDA's Oncology Center of Excellence (OCE). One of the OCE's initiatives is the Patient Focused Drug Development (PFDD) programme which is looking at improving the measurement of clinical outcomes, assessed through measures such as patient reported outcomes (PROs).

Enthusiasm for Clinical Outcomes: Why Now?

Dr Kluetz explained that recent legislation such as the 21st Century Cures Act in the United States asks the FDA to review and communicate patient experience data as part of their regulatory assessments and this has spurred renewed interest in PROs. Technology is improving capabilities and PROs can now be captured electronically. This produces more structured clinical data leading to increased efficiencies in clinical trials and a future pipeline of real world patient data.

"This can even be done at home using the patient's own device, such as their iPhone," said Dr Kluetz. "The use of wearable devices and sensors to capture patient data is another area of promising research," he added.

Dr Kluetz said that clinical care is also increasingly using PRO measures. He said: "The more PROs are used in clinical management the more relevant they become to regulators, as we try to measure things that have meaningful impact for patients and may change treatment strategies." Patients want more rigorous information on the effect of cancer drugs on quality of life, over and above the traditional endpoints of safety and efficacy. They want to make an informed choice as to which treatment is right for them.

Patient experience data can be measured throughout all stages of the drug development process, from translational research to clinical studies, pre-market review and post market. Dr Kluetz recommended that companies include PROs earlier in the drug development process as the traditional concept of Phase I, Phase II, Phase III is becoming less discrete and an earlier trial could turn out to be a registration trial (a trial that leads to a product being registered).

When asked if using big data as a 'synthetic control arm' in a trial could replace the need for randomised trials, Dr Kluetz replied: "There are many prognostic factors, some known and others unknown, which makes randomisation in a controlled clinical trial important in order to balance these factors and avoid a false conclusion. Even known prognostic factors may not be available or accurately characterised in real world data sources. One way to allow all patients access to investigational drugs in a randomised trial is to allow cross-over at progression, and we are increasingly seeing cross-over in these trials where early information on the drug's activity is promising."

Dr Kluetz emphasised that successful patient-focused drug development must constitute a dialogue between patients, clinicians, trialists and health policy leaders. It recognises that patients are experts in how they experience their disease and they understand what is important to them. Clinicians, on the other hand, know how to measure outcomes and how to design and conduct clinical trials. Working together, we hope to identify scientifically rigorous and feasible patient-centred trials.

Chief of the Neuro-Oncology Branch at the National Cancer Institute Dr Mark Gilbert

Linda Powers, CEO of Northwest Biotherapeutics, puts a question to Dr Paul Kluetz of the US FDA

How can trials be more patient-friendly?

An important aspect of the FDA's PFDD programme is how to make clinical trials more patient-friendly. This includes making it easier for patients to access clinical trials, for example, by broadening eligibility criteria and offering trials which are localised near a patient's home (so-called "decentralised" trials). Another important aspect of PFDD is "measuring what matters to patients" and this includes measuring symptoms, function and other aspects of health-related quality of life.

Dr Kluetz said that to maximise the potential of using patient reported data in clinical trials and regulatory decision making, we need to agree on a standard set of core clinical outcomes to measure. These core outcomes must be important to patients, sensitive to the intervention, and able to inform regulatory decisions. The core clinical outcomes that the FDA is investigating include:

- disease symptoms
- symptomatic adverse events
- physical function, or the ability to carry out activities that require physical strength
- ability to work and perform leisure activities

The core patient reported outcomes can complement traditional measures for efficacy and safety to provide a comprehensive set of data elements. The number of hospitalisations or emergency department (ED) visits can also be looked at as part of the balance between benefit and toxicity. The aim is to produce a consistent set of analytics and endpoints which can be standardised for use in multiple trials.

Responding to a question from IBTA Chair Kathy Oliver about caregiver reported outcomes, Dr Kluetz said that observer reported outcomes are useful in certain situations, for example, with children or observing cognitive deficits. However caregiver reported outcomes tend to be useful when the deficits are observable - there is still a difficulty with unobservable deficits such as fatigue or nausea.

How do core outcomes differ for brain tumour patients?

To account for the unique challenges presented by brain tumour patients, the FDA is part of a core outcomes working group which - in addition to toxicity, physical function and role function - is looking at issues such as pain, difficulty communicating, perceived cognition and seizures.

Improving the analysis of PRO data and establishing how best to communicate the data are the next steps to be undertaken, said Dr Kluetz. He sees international collaboration with various stakeholder groups, including patient advocates, as critical in both of these steps.

"What needs to happen is for international stakeholders to agree upon the standards. It's not going to do any good for the FDA to have one standard, the EMA to have a different standard, and the German payers to have another standard," he said. The European Organisation for Research and Treatment of Cancer (EORTC – based in Brussels, Belgium) is leading a collaborative effort in identifying standard approaches to PRO analyses with their SISAQOL initiative - Setting International Standards in Analysing Patient-Reported Outcomes and Quality of Life Endpoints. The IBTA has been involved in the SISAQOL consortium for the last four years and continues to be involved in ongoing SISAQOL work.

Likewise, the FDA is not advancing their work with PROs in a vacuum, having hosted multiple workshops with international regulatory, payer, and patient and academic groups to discuss issues such as what clinical outcomes to measure and how to measure them, and exploring ways to measure physical function. In terms of communicating patient experience data, the FDA is making progress on the inclusion of more PRO data on product labels. This is a complex issue as each international regulatory body has a different context in which they apply their regulations. For example, in the United States the product label is a legal document which amounts to direct-to-consumer advertising, something which is not permitted in other countries. ■

Narrative Medicine: An Introduction

Presenter: Dr Elizabeth Anne Scharle, Assistant Professor of Medicine in the Division of General Medicine and Geriatrics, Northwestern Memorial Hospital, Chicago, Illinois, US)

Key Points

- Narrative Medicine explores the connections between medicine and the humanities, with stories being a central part.
- Narrative Medicine involves a specific methodology of close reading, reflective writing and discussion of shared experience.
- The three basic tenets of Narrative Medicine are attention, representation and affiliation.
- Narrative Medicine leads to more compassionate care and more meaningful experience.

What is Narrative Medicine?

"Life is full of stories: happy, sad, stories of joy, and of suffering. We are all here because of stories," said Dr Elizabeth Anne Scharle.

"Stories enrich our lives and bring meaning to our experiences. But we have to stop to really listen to those stories. To take them in, to honour them, in order to appreciate them, and to allow them to transform us."

Dr Scharle's opening slide was the 1907 oil painting "The Sick Child" by Norwegian painter Edvard Munch. The painting depicts a pale-looking child propped up in her bed, holding the hands of a woman sitting beside her. The woman is dressed in black and her head is bowed.

"I ask you all to take a moment to encounter this painting," said Dr Scharle. "You don't need any words to feel the story being told in this painting. The grief, the suffering, the pain, the compassion – told through images, through brushstrokes, through symbols."

Dr Scharle explained that with this painting Edvard Munch tried to capture the story of his older sister, Sophie Joanne, moments before her death. "Narrative medicine helps us look more closely at this painting and the story it tells, and then helps us connect what we've learned from it with what we experience in our day-to-day lives."

A more formal definition of narrative medicine comes from Dr Rita Charon, Dr Scharle's mentor and the person widely recognised as the formal founder of the Narrative Medicine field. Narrative Medicine is "medicine practiced with the narrative competence to recognise, absorb, interpret and be moved by the stories of illness."

"Stories are the central part of Narrative Medicine," explained Dr Scharle. "It explores the connections between medicine and the humanities."

Dr Scharle said that each branch of the humanities can teach us something different about stories, including literary studies, philosophy and history. "The humanities inform the practice of medicine, and ultimately help participants understand and address the complex human experiences inherent in health, illness and death. These are perhaps the most uniting experiences of all, and lie underneath most of the stories we tell," said Dr Scharle.

Narrative Medicine involves a specific methodology comprised of close reading, reflective writing, and discussion of shared experience. (Close reading is thoughtful, critical analysis of a text that focuses on significant details or patterns in order to develop a deep, precise understanding of the text's form, craft and meanings.) Referring back to the painting, Dr Scharle described the process of examining a painting, writing about it, and sharing that writing. From this process come the three basic tenets of narrative medicine:

Dr Elizabeth Anne Scharle

- **attention** – close empathetic listening.
- **representation** – the power of story telling
- **affiliation** – creating meaning through shared experience

"Attention teaches participants to be attuned to the verbal and non-verbal cues in our stories. From our words, to our appearances, to our posture," explained Dr Scharle.

Representation speaks to the power of story-telling. We bear witness to the stories when we hear them, and when we retell them, we further honour them and imbue them with our own sense of selves. Dr Scharle added that in medicine we listen to and retell stories all time – as healthcare providers, as caregivers, to other providers and in the electronic medical record. As patients - recipients of care - stories are retold to other patients and reflect on our experiences.

Perhaps the most critical function of narrative medicine is affiliation, which cuts across the divide between caregivers and recipients of care, uniting us together as we begin to understand that we have the same experiences, the same emotions and ultimately the same stories.

Why Narrative Medicine?

"Narrative medicine is wonderful in theory but even more wonderful in practice," said Dr Scharle. "Through the exploration of texts, participants learn to listen more deeply and their capacity to be attentive is heightened. This leads to more compassionate care and more meaningful experience."

She added: "The dedicated space and time for reflective writing allows for critical processing of experience and fosters innate creativity, leading to increased capacity for empathy." "Participants are inspired to find new ways of relating to themselves and to others, leading to the formation of more meaningful relationships. As care providers, this ultimately means that we become not only more humane, but more efficient, effective providers."

How can a process of deeper listening lead to more efficiency? Dr Scharle explained that if we truly listen, we get to know our patients and each other in ways beyond just what is written in the electronic medical record, and perhaps we won't ask the same set of questions twice. "We will be more attuned to the many cues our patients give as to their real sense of wellness," she said.

Dr Scharle suggested that: "There has never been a more critical need for Narrative Medicine. Technology has brought wonderful new developments to the ways we understand and treat disease, but some of these interventions push against the human bonds that unite us. Without a central understanding of what is at medicine's core – a relationship between people, illness, a desire to restore wellness – we have lost the very definition of what it means to be human."

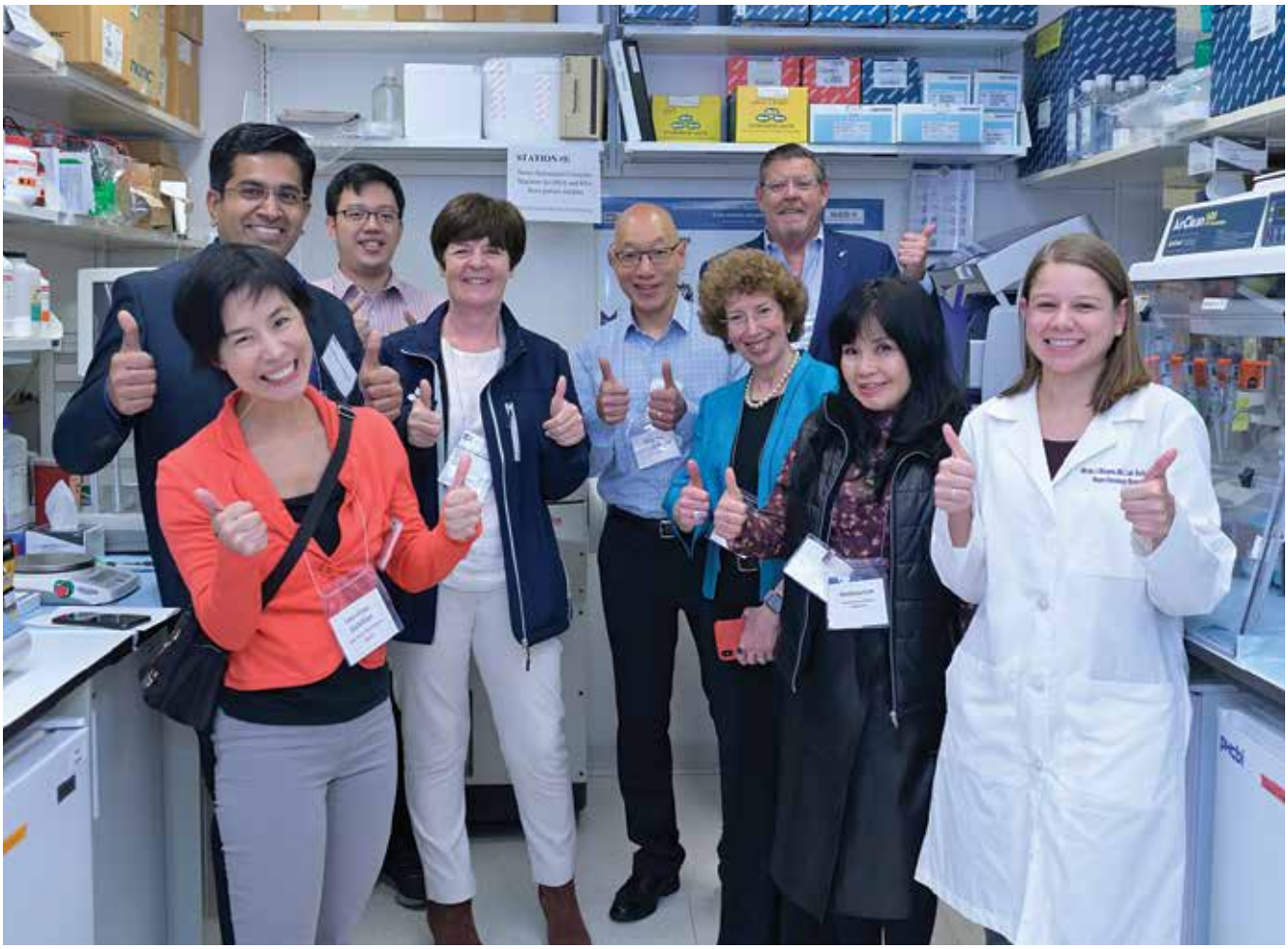
Who is Narrative medicine for?

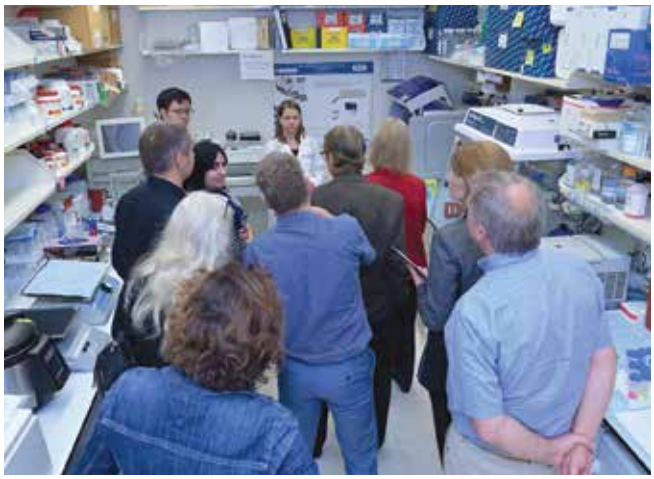
"Narrative Medicine is for everyone!" said Dr Scharle. "The experiences of illness and death are universal, and so the discussion of these experiences is open to everyone."

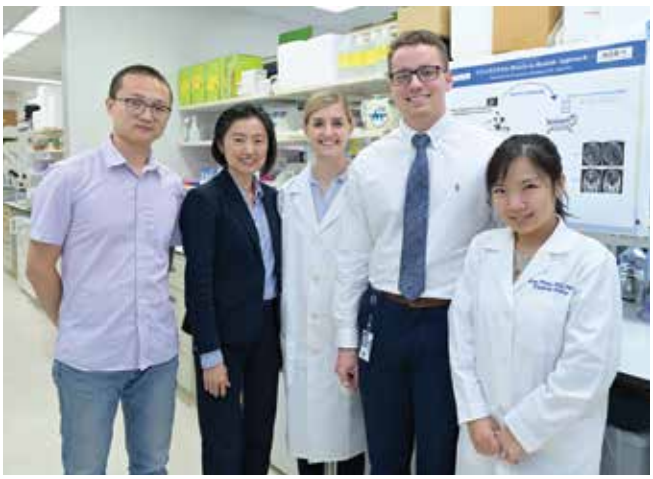
Specific settings in which Narrative Medicine is practiced include patient groups, medical education and training, and multidisciplinary healthcare providers. Dr Scharle's particular interest has been to practice Narrative Medicine with medical residents who are at a critical phase of their training. This has led to a renewed focus on ways to cultivate wellness and resiliency among medical trainees, who - due to a heavy and stressful workload - are at risk of burnout, depression and even suicide.

"Through thoughtful reflection, trainees find a new sense of meaning and connection to their work, to patients, and to each other," said Dr Scharle ■

Tour of the Neuro-Oncology Labs at NIH







A highlight on the first day of the IBTA Summit was the NIH Neuro-Oncology Laboratory Tour.

Prior to the tour commencing, Dr Mark Gilbert gave a brief presentation introducing the Neuro-Oncology Branch.

Following Dr Gilbert's presentation, delegates divided into four groups and were escorted by NIH staff to the Neuro-Oncology Branch laboratories. Here they were given a guided tour of five lab stations, each with a specific research focus:

1. **Translational Immunology Lab – Dr Mark Gilbert**
   - Improving the efficacy of immunotherapy for patients with CNS cancers, particularly GBM, by analysing patient immune cells to find distinguishable patterns
2. **Molecular and Cell Biology Lab – Dr Chun Zhang Yang**
   - Understanding a fundamental question in brain tumour therapeutics - therapy resistance - by studying the unique pattern of DNA mutations and next generation molecular targeting strategy
3. **Translational Research Lab – Dr Jing Wu**
   - Focusing on the development of new therapies to treat brain tumour patients by conducting pre-clinical studies of new drugs and performing patient-based research
4. **Cancer Metabolism Lab – Dr Mioara Larion**
   - Understanding how brain cancer cells utilise their nutrients to grow and divide, what and why they prefer to eat, in order to understand how we can starve them

5. **Outcomes Lab – Dr Terri Armstrong**
   - Utilising patient reported outcomes to understand symptom burden and improve patients' quality of life and analysing genetics to improve treatment and outcomes

The visit to Dr Jing Wu's Translational Research Lab offered a chance for Summit delegates to see the "bench-to-bedside" translational research approach in action. Dr Wu's team have conducted pre-clinical studies with TG02 (zotiraciclib) which provided the rationale for a Phase I clinical trial to test the safety and efficacy in patients with recurrent high grade glioma. ■

Day Two: Friday 11 October 2019

National Institutes of Health Bethesda, Maryland Campus

Plenary Session 4

Co-chairs: Chris Tse, Senior Advisor International Brain Tumour Alliance (New Zealand) and Dr Nitin Garg, Consultant Neurosurgeon and Founding Director, Brain Tumour Support and Awareness Group (India)

Brain Tumours in Portugal

Presenter: Dr Andreia Capela (Medical Oncologist, Centro Hospitalar Vila Nova de Gaia/ Espinho, Portugal)

Dr Andreia Capela from Portugal

Dr Andreia Capela is the medical oncologist responsible for the Neuro-Oncology Board at Centro Hospitalar Vila Nova de Gaia/ Espinho in northwest Portugal. She has a special interest in supportive cancer care and the holistic rehabilitation of people living with and beyond cancer.

Dr Capela explained that Portugal has a system of universal, free healthcare called the National Health Service (Serviço Nacional de Saúde - SNS) which operates under the Directorate General of Health. Most cancer patients are treated under this system with the remainder covered by private healthcare.

Cancer treatment in Portugal

Cancer treatment under the SNS provides patients with a number of rights and benefits, Dr Capela explained. These included equal rights for people with low grade tumours, exemptions from certain fees and taxes, revision of home loans and reduced medicine costs.

Cancer is a major health burden in Portugal, which has a population of 10.2 million. There are 58,199 cancer diagnoses and 28,960 cancer deaths each year, according to the World Health Organisation GLOBOCAN 2018 report. Brain and central nervous system cancers were the 14th most common cancer type with 1,225 new cases (2.1%) and 1,042 deaths (3.6%).

Brain tumour treatment

In terms of brain tumour treatment, Portugal has twelve neurosurgical centres, with the majority located around the main population centres of Lisbon in the west and Porto in the northwest. There are 42 medical oncology departments and four pediatric neuro-oncology departments across Portugal.

Kathy and Gordon Oliver, Co-Directors of the IBTA, listening to Dr Capela's description of brain tumours in Portugal

Brain tumour research, both clinical and pre-clinical, is carried out in four research centres however, Dr Capela lamented the general lack of brain tumour clinical trials available to patients in Portugal and said more research is desperately needed. Furthermore, she added, patients do not generally travel abroad for treatment, due to financial constraints.

Portugal does not have its own set of clinical guidelines for brain and central nervous system tumours so clinicians use various international guidelines. Similarly, there is no national strategy or recommendations for supportive care and rehabilitation for cancer patients. This means that interventions are driven locally, there are no specialised rehabilitation centres and no structured rehabilitation interventions. This is another area in which more effort and resources are needed, Dr Capela said.

There are four professional organisations available for clinicians treating brain and central nervous system tumours. In terms of patient organisations, there is a national anti-cancer league, an association for tuberous sclerosis patients and some local groups, but there is no national brain tumour patient organisation.

Brain tumour services at the Centro Hospitalar Vila Nova de Gaia/Espinho

Dr Capela gave a brief introduction about brain tumour services at the Centro Hospitalar Vila Nove de Gaia/Espinho. In 2018, the neurosurgical department treated 68 brain tumour patients, 30 males and 38 females, with an average age of 63.5 years (25 – 85 years). The most common tumour type was meningioma, followed by glioblastoma.

In the area of supportive care and rehabilitation, the hospital provided physiotherapy, occupational therapy and speech therapy services through local clinics. Additional support services were available to low grade brain tumour patients, including neuropsychology and acute rehabilitation (Centro Reabilitação do Norte) and professional and neurocognitive rehabilitation (Centro de Reabilitação Profissional de Gaia).

Since 2018, the hospital has participated in the International Brain Tumour Awareness Week (Semana de Alerta Tumores Cerebrais). For the 2019 Awareness Week, information was broadcast on hospital television, a local gym held relaxation sessions for patients and friends, and all participants came together over a coffee break.

Finally Dr Capela shared her plans for 2020 awareness-raising activities, which include:

- Gaining institutional support from Associação Portuguesa de Neuro-Oncologia
- Forming a national strategy for brain tumour patient advocacy
- Addressing both adult and pediatric patients

"Giving formation, to inform and educate patients and caregivers is a professional responsibility," said Dr Capela. ■

Genetic Counselling in the Neuro-Oncology Clinic: Evaluating Family and Medical History to Determine the Risk of Developing Brain Tumours

Presenter: Dr Margarita Raygada (Genetic Counsellor, NCI-CONNECT, NCI, NIH) General Medicine and Geriatrics, Northwestern Memorial Hospital, Chicago, Illinois, US)

Key Points

- Although over 50 hereditary cancer syndromes have been identified, it is estimated that only around 10% of cancers are caused by having a genetic predisposition to cancer.
- A negative family history of cancer does not exclude a hereditary cancer syndrome.
- Very few CNS cancers are hereditary however some known syndromes have been identified.
- Some known hereditary cancer syndromes are associated with common phenotypical features which can alert the physician that genetic testing is warranted.

■ A genetic counsellor works with patients and their families to help them understand genetic testing, guide them through the process and help them make informed choices based on their genetic testing results.

Dr Margarita Raygada, a genetic counsellor for NCI-CONNECT

Dr Margarita Raygada is an oncology genetic counsellor and geneticist at the National Institutes of Health (NIH). She helps patients understand the role of genetic testing, as well as the impact of the results on the management of their condition. She also addresses the risk to relatives of developing a brain tumour and explains the research goals of the genomic component of the neuro-oncology clinic.

"Hereditary cancer syndromes are not common," Dr Raygada said. Although over 50 hereditary cancer syndromes have been identified, it is estimated that only around 10% of cancers are caused by having a genetic predisposition to cancer. It is important that patients affected by hereditary cancer syndromes are identified so that they and their family members can be monitored.

Family history and risk

A positive family history of cancer helps identify patients at risk. However, a positive cancer family history in itself is usually not enough to diagnose a cancer syndrome with certainty, especially when common type cancers are involved. Chance alone may cause the clustering of cancer (especially in large families), and an appreciation of the size of the family, the number of unaffected relatives, and their place in the family tree is important. Shared environmental risk factors may contribute to the familial occurrence of cancer, for example, a familial habit of heavy smoking to the clustering of lung cancer. These factors should be ascertained.

Likewise, a negative family history of cancer does not exclude a familial cancer syndrome for several reasons. Virtually none of the germline mutations involved in hereditary cancer have a 100% penetrance. Families may be small, there may be insufficient information including lack of knowledge of the family history, the death of parents and other relatives at a relatively young age from non-cancer causes. Also, cancer patients may have a new, de novo (first time) mutation and therefore be the first in their family with a syndrome.

Glial Tumours – predisposition syndromes

Very few central nervous system cancers are hereditary however, Dr Raygada introduced some of the known syndromes, the corresponding genes and the brain tumour type:

- **Familial atypical multiple mole melanoma (FAMM)** – CDKN2A [astrocytoma]
- **Neurofibromatosis type 1 (NF1)** – NF1 [optic glioma, astrocytoma, medulloblastoma]
- **Tuberous sclerosis complex (TSC)** – TSC1/2 [subependymal giant cell astrocytoma, cortical hamartomas (tubers), subcortical glioneural, hamartomas]
- **Neurofibromatosis type 2 (NF2)** – NF2 [vestibular and spinal schwannomas, meningioma, glioma, ependymoma]
- **Multiple endocrine neoplasia type 1 (MEN1)** – MEN1 [pituitary, meningioma, ependymoma]
- **Lynch syndrome/CMMR-D** – MLH1/MSH2/MSH6/PMS2/EPCAM [GBM, gliomas]
- **Li Fraumeni syndrome (LFS)** – TP53 [medulloblastoma, GBM, astrocytoma, choroid plexus carcinoma, glioma]
- POT1 mutation [gliomas]

Embryonal Tumours – predisposition syndromes

Known syndromes for embryonal tumours include:

- ALK [medulloblastoma, neuroblastoma, ganglioneuroma]
- **Gorlin syndrome** – PTCH1 [medulloblastoma, meningioma]
- **Gorlin syndrome** – SUFU [medulloblastoma]
- **Li-Fraumeni syndrome** – TP53 [medulloblastoma, GBM, astrocytoma, choroid plexus carcinoma]
- NBN [medulloblastoma, ganglioglioma]
- **Familial adenomatous polyposis (FAP)** – APC [medulloblastoma]

- **Rhabdoid tumour predisposition syndrome/schwanomatosis** – SMARCA4/SMARCB1/LZTR1 [schwannomas, atypical teratoid/rhabdoid tumours (AT/RT)]
- **DICER1 syndrome** – DICER1 [pineoblastoma, pituitary blastoma]
- **Hereditary retinoblastoma** – RB1 [pineoblastoma]

Meningeal Tumours – predisposition syndromes

Known syndromes for meningeal tumours include:

- **Multiple endocrine neoplasia type 1 (MEN1)** – MEN1 [pituitary, meningioma, ependymoma]
- **Gorlin syndrome** – PTCH1 [medulloblastoma, meningioma]
- **PTEN hamartomatous tumour syndrome** – PTEN [meningioma, dysplastic cerebellar gangliocytoma (Lhermitte-Duclos)]
- SMARCE1 [meningioma]
- **Neurofibromatosis type 2 (NF2)** – NF2 [vestibular and spinal schwannomas, meningioma, glioma, ependymoma]

Pituitary Tumours – predisposition syndromes

Known syndromes for pituitary tumours include:

- **Familial isolated pituitary adenoma (FIPA)** – AIP [pituitary]
- **Multiple endocrine neoplasia type 4 (MEN4)** – CDKN1B [pituitary]
- **DICER1 syndrome** – DICER1 [pineoblastoma, pituitary blastoma]
- **Multiple endocrine neoplasia type 1 (MEN1)** – MEN1 [pituitary, meningioma, ependymoma]
- **Carney complex** – PRKAR1A [schwannomas, pituitary]

Dr Raygada explained that some known hereditary cancer syndromes are associated with phenotypical commonalities. These clinical features are physical manifestations which can alert the treating physician that further genetic testing is warranted.

Genetic Testing – germline and somatic

Dr Raygada explained the different types of genetic testing. Somatic testing is done on tumour-derived DNA and is looking for mutations in the cancer cells, which are not inherited. Germline testing is usually done on DNA from a blood or saliva sample and is looking for germline mutations which can be passed down from generation to generation.

The type of test used will depend on the patient's circumstances. Single gene testing should be done if there is a suspected syndrome or known familial mutation. A panel test should be done if there is a suspected group of syndromes based on family history, phenotype, or medical history. Whole exome sequencing is usually only done for research/gene discovery purposes, or when all previous tests have been negative and a hereditary condition is still suspected..

Results of tumour panels sometimes have indicators for confirmatory germline testing. These include: 1) tumour mutational burden is high or the tumour is of a type when repetitive DNA sequences termed "microsatellites" are prone to a high number of mutations (microsatellite instability-high (MSI-H); 2) there are founder mutations in the somatic results; or 3) BRCA1/2, PALB2 or MMR mutations are found in the somatic results.

Dr Raygada introduced the role of genetic counsellors as: "Working with patients and their families to help them understand genetic testing, guide them through the process and help them make informed choices based on their genetic testing results." ■

Society Update: Society for Neuro-Oncology (SNO)

Presenter: Chas Haynes, JD, Executive Director, Society for Neuro-Oncology

Chas Haynes, Executive Director of the Society for Neuro-Oncology (SNO) in the United States

The Society for Neuro-Oncology (SNO) is a multidisciplinary organisation dedicated to promoting advances in neuro-oncology through research and education. Since its formation in 1996, SNO has grown into a dynamic and diverse organisation with worldwide membership. Chas Haynes has served as its Executive Director since 2006. He presented an update on the Society's activities to IBTA Summit participants. Chas explained that SNO has four core functions: 1) the SNO annual meeting, 2) publishing, 3) boutique meetings, and 4) committees and outreach.

The SNO Annual Scientific Meeting

The SNO annual meeting is the "engine" of SNO and its flagship event. The meeting has grown impressively in the last ten years. In 2010 it attracted just over 1,000 attendees and 500 abstracts. The 2019 meeting in Phoenix, Arizona attracted over 2,600 attendees from 48 countries, reflecting the Society's strong international reputation, and around 1,300 abstracts. There were also a number of pre-conference meetings in Phoenix. In 2019, SNO organised two additional meetings: the "Pediatric Basic and Translational Neuro-Oncology Conference" in San Francisco and the "Inaugural Conference on Brain Metastases" in New York.

SNO Publishing

SNO's flagship publication is the monthly journal "Neuro-Oncology", published by Oxford University Press. The journal has also experienced impressive growth since its inception, as rated by a variety of metrics, including: Science Citation Index (SCI) Impact Factor (currently 10.91), download activity, and number of articles cited. Under current Editor-in-Chief Dr Ken Aldape, Neuro-Oncology is ranked 13th of 229 oncology journals and 8th of 199 clinical neurology journals.

Following the success of Neuro-Oncology, SNO launched "Neuro-Oncology Practice" in 2014 and its newest journal "Neuro-Oncology Advances" in 2019. Neuro-Oncology Practice, under Editor-in-Chief Dr Susan Chang, focuses on the applied aspects of neuro-oncology and fills the need for practical and educational content. Neuro-Oncology Advances, under Editor-in-Chief Dr Gelareh Zadeh, is an open access journal with a broader scope than the other two SNO publications, covering basic, applied, and clinical investigations in all areas as they relate to cancer and the nervous system.

Developing Countries Programme and International Outreach

SNO understands that brain tumours do not recognise geographical boundaries. To promote neuro-oncology knowledge and research in less developed regions of the world, SNO participates in a World Health Organisation (WHO) Developing Countries Programme to provide SNO journals free, or at a heavily reduced rate, to non-profit institutions in developing countries.

SNO's International Outreach initiatives are led by Drs Jason Huse (US) and Mustafa Khasraw (Australia). This initiative offers developing nation travel scholarships to the SNO Annual Scientific Meeting and holds an Outreach Luncheon at the annual meeting. It also manages the SNO-Wilkins Barrick Initiative, an annual course in neuro-oncology in the developing world, in conjunction with the Greg Wilkins-Barrick Chair at the University Health Network, University of Toronto. Courses have been held in Malaysia, Morocco, Sri Lanka, Peru, Nigeria (marking the launch of the Society for Neuro-Oncology in Sub-Saharan Africa, SNOSSA) and South Africa. The Nigeria course was preceded by the joint SNO-Wilkins Barrick and IBTA Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) meeting in London in 2017.

World Federation of Neuro-Oncology Societies (WFNOS)

Together with the Asian Society for Neuro-Oncology (ASNO) and the European Association of Neuro-Oncology (EANO), SNO has been instrumental in the formation of the World Federation of Neuro-Oncology Societies (WFNOS) and their efforts to unite neuro-oncology societies around the globe.

SNO Governance and Management

SNO is governed by a leadership team headed by President Dr Patrick Wen and Vice-President Dr Gelareh Zadeh, and a board of eleven directors representing all specialist disciplines involved in brain tumour treatment. The SNO Foundation, which is tasked with ensuring long term financial stability for SNO, has a board of five, chaired by Dr David Reardon. Executive Director Chas Haynes leads the management team which looks after day-to-day operations.

Online Resources

A recent development has been the addition of online resources on the SNO website. The SNO Online Education Center promotes advancement in neuro-oncology research and education by providing access to online resources such as webinars, annual meeting presentations and continuing education. The first webinar: "Understanding Molecular Characteristics of Tumors and Implications for Treatment" by Dr Craig Horbinski was held in September 2019 and attended by over 250 people. ■

Society Update: Society for Neuro-Oncology for Sub-Saharan Africa Update

Presenter: Edjah Nduom, M.D., Neurosurgeon, National Institute of Neurological Disorders and Stroke, NIH, Society for Neuro-Oncology Sub-Saharan Africa

DR Edjah Nduom is a neurosurgical oncologist in the Surgical Neurology Branch of the National Institute of Neurological Disorders and Stroke (NINDS) at the NIH, where he also heads the Brain Tumor Immunotherapy Unit. Dr Nduom is a founding steering committee

Dr Edjah Nduom, neurosurgeon at the National Institutes of Health (NIH), gives an update on the latest news from the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA)

member of the Society for Neuro-Oncology Sub-Saharan Africa (SNOSSA) and gave delegates an update on the Society's activities.

SNOSSA History

Dr Nduom reminded delegates that SNOSSA was formed out of a collective which came together at the International Brain Tumour Alliance (IBTA) meeting in London in 2017. For a full report of this meeting, see the official report at https://issuu.com/ibta-org/docs/ibta_ssanoc-report_final_20mar2018. The following year, SNOSSA held its inaugural Annual Meeting in conjunction with the Continental Association of African Neurological Surgeons (CAANS) Annual Meeting in Abuja, Nigeria. The inaugural meeting in 2018 had some significant challenges, explained Dr Nduom. These included high costs, a late start for planning, and other start-up difficulties.

The second annual SNOSSA meeting was held on 7-8 August 2019 in Cape Town, South Africa, in collaboration with the annual South African Paediatric Brain Tumour Workshop. The meeting was held in conjunction with the Society of Neurosurgeons of South Africa (SNSA) meeting and the South African Congress of Oncology. The theme of this SNOSSA meeting was "Multi-disciplinary Management of Patients with Brain Tumours."

With the support of sponsorship, SNOSSA was able to offer travel scholarships to 33 physicians, nurses, advocacy workers and allied health professionals from 13 countries to attend the 2019 Annual Meeting. Over 160 delegates participated in the meeting, including an impressive international faculty.

Ongoing Efforts

Dr Nduom highlighted the following ongoing efforts for the development of SNOSSA:

- recently became a member of the World Federation of Neuro-Oncology Societies
- registration as a non-profit in the United States
- website revamp to save costs
- planning for the 2020 SNOSSA meeting in Ghana.

The 2020 Annual Meeting of SNOSSA is tentatively scheduled for 24-26 June in Accra, Ghana. This will be the first standalone SNOSSA conference. There are plans to associate the event with a World Federation of Neurological Surgeons (WFNS) neurosurgical course, to be co-chaired by Dr Isabelle Germano, a US-based neurosurgeon. ■

Breakaway Pick and Mix Sessions

EIGHT breakaway "Pick and Mix Sessions" were spread over two 60-minute periods with four sessions held concurrently in each period. Summit delegates were able to attend two sessions each. The sessions covered a wide range of specialist topics, which were presented by one or more experts. Some sessions followed a workshop format and all sessions offered ample opportunity for discussion and active participation from delegates. ■

Concurrent Pick and Mix Session 1

Returning to School After a Brain Tumour Diagnosis

Facilitator: Kathy Riley, Vice President of Family Support, Pediatric Brain Tumor Foundation (US)

Presenter: Vicky Ringer, Co-Founder, Levi's Star Children's Brain Tumour Charity (UK)

Vicky Ringer led a workshop at the IBTA Summit about returning to school after a brain tumour diagnosis

Session facilitator Kathy Riley (Pediatric Brain Tumor Foundation, US) discusses the "Returning to School After a Brain Tumour Diagnosis" session with presenter Vicky Ringer (Levi's Star Children's Brain Tumour Charity, UK)

THIS workshop, presented by Vicky Ringer, Co-Founder, Levi's Star Children's Brain Tumour Charity focused on how children living with the effects of a brain tumour need to be supported upon return to school and throughout their school career. Content of the workshop included firstly describing the specialist educational outreach support service offered in the North of England by Levi's Star, as a model of good practice. The service not only helps families navigate the SEN system and secure appropriate and ongoing support for their child at school, but helps the school identify the learning and support needs of the child. The workshop included discussion about the need for a pathway of school support for childhood brain tumour survivors and what that pathway should include.

There was general agreement among workshop participants that schools are in a prime position to help children with brain tumours cope with the changes and unique, ongoing challenges they face. However, it was also recognised that teachers and key school staff may lack the knowledge and awareness about the range of difficulties children with brain tumours can experience, and what level of classroom support and intervention should be implemented.

Working towards a common aim

Delegates were asked to take part in tasks which helped them consider how classroom learning can be affected for childhood brain tumour survivors. To add to the discussion, delegates were able to provide examples of school support for children with brain tumours in other countries.

It was clear that everyone had a common aim: to ensure quality of survivorship for children living with the effects of a brain tumour. Discussing the central role school can and should play in helping childhood brain tumour survivors reach their full

IBTA Co-Director Gordon Oliver participated in the returning to school workshop

academic and social potential, reinforced the general consensus that schools are in a prime position to positively impact future life chances for this vulnerable group of children.

The workshop ended with delegates creating a 'Wall of Hope' for the future of children with brain tumours. Such 'hopes' demonstrated a shared desire for children with brain tumours to reach their full potential at school, to have friends, to be appropriately supported throughout school, treated with respect and understanding, and to be happy. ■

Concurrent Pick and Mix Session 2

Fundraising for Brain Tumour Research and Support in an Era of Economic Challenges

Facilitator: Hugh Adams, Head of PR and Stakeholder Relations, Brain Tumour Research (UK)

Presenter: Robin Meltzer, Director of Fundraising and Marketing, Brain Tumour Research (UK)

Robin Meltzer, Director of Fundraising and Marketing at Brain Tumour Research in the United Kingdom spoke about the different approaches to fundraising that exist in not-for-profits

Brain Tumour Research's Head of Stakeholder Engagement Hugh Adams facilitated the session on fundraising for brain tumour research

BRAIN Tumour Research's (UK), Robin Meltzer (Director of Fundraising & Marketing) presented a session facilitated by Hugh Adams (Head of Stakeholder Engagement) about the fundraising landscape and how to engage supporters in an era of economic challenges.

The session began with an overview of the principle of 'Supporter Centricity' within fundraising, which places supporters of a charity at the heart of the organisation. The idea of supporter centricity is that supporters should be recognised, thanked and valued in a non-transactional way that builds donor loyalty.

Robin summarised the concept of 'relationship fundraising', an established academic principle of philanthropy that likens the relationship between a fundraising professional and a donor to a friendship in which the two sides build trust, provide mutually beneficial experiences and gradually begin to share the same priorities and outlook. Such fundraising practices elevate fundraising beyond a consideration of return on investment and towards a more holistic appreciation of the 'lifetime value' of a supporter. These techniques help insulate a charity against economic downturns in the market in which they operate.

Taking questions from participants in the room, Robin and Hugh led a discussion about which income types may be inherently more secure and free from external risk.

The importance of thanking supporters

The session then moved on to the importance of thanking,

and how organisations which invest time and resources into an efficient and warm thanking process reap the benefits from a supporter base which is pleasantly surprised by the personalisation of thank you communications. The group discussed the importance of charities making a conscious decision where on the 'Speed Versus Quality' axis their thanking process should fit. Hugh and Robin said that it is perfectly valid to take a little bit longer to thank people if the quality of the thank you communication can "delight and surprise the supporter".

There was considerable time dedicated to a discussion of donor and fundraising motivations. Many different things drive a decision to donate or fundraise, including anger, sadness, grief, inspiration, social recognition, cultural influences and simply being asked by the right person in the right way. Understanding the motivation for giving is pivotal to protecting an organisation's ability to fundraise if external factors (political, economic, social or technological) deteriorate.

In-Memory Fundraising Groups

The session ended with an examination of the In-Memory Fundraising Groups set up to raise money for Brain Tumour Research. These groups have their own identity, their own logos and their own fundraising targets but they operate under the auspices of Brain Tumour Research and adhere to all of its fundraising rules and regulations. This allows supporters to pay proper, meaningful, visible tribute to those who have been lost to a brain tumour without the stress of starting their own charity. This was considered by many in the room to be a good case study in supporter centricity.

This group session allowed attendees to hear experiences from organisations in every type of donor market, from developing to highly developed. There were some universal themes and other areas where there was true diversity of both process and progress. Several delegates expressed their view that further sessions on fundraising and the principles of 'supporter care' would be beneficial in future years with a view to growing collectively both the size and the impact of the charities in the global brain tumour patient advocacy community. ■

Concurrent Pick and Mix Session 3

Support Groups 101 - Tips on Managing a Brain Tumour Support Group

Facilitators: Sharon Lamb, Clinical Nurse Specialist, IBTA Senior Advisor (US) and Tina Mitchell Skinner, Founder and CEO, Brain Tumour Support (UK)

WORKSHOPS offering the opportunity to talk about support within the brain tumour community are always extremely popular at the IBTA Summits. The make-up of this pick and mix session was extremely diverse and so was the range of questions.

Individual participants were asked what they wanted to get out of the session and these responses were written on a flip chart. The aim was to try to provide the answers to those questions from the session participants. Those present ranged from clinical, scientific, pharmaceutical and charity backgrounds, all with a story to tell. As with many of these sessions, people like to share and love to learn from the experiences of others.

Sharing best practice

Best practice from other countries was shared. The role of clinical trials supporting brain tumour patients on their journey was once again a popular topic but highlighted the challenge that patients aren't always able to access these research studies. Participants at the Summit whose organisations offer regular support groups were able to give hints and tips on what these groups could look like with the potential pit falls. Challenges around running support groups were also addressed, with sustainability as an issue. Discussions also took place around on-line support, such as Facebook groups and the monitoring of these. The session participants talked about how these groups need clear guidelines and yet they are a wonderful way of connecting with those who don't like the face-to-face support group setting.

At the end of the session, Tina and Sharon distributed handouts about running support groups.

Tina Mitchell Skinner (Brain Tumour Support, UK) and Sharon Lamb (IBTA Senior Advisor (USA) facilitated the workshop on managing brain tumour support groups at the IBTA Summit

Jean Arzbaecher, RN, APN is an IBTA Senior Advisor from the United States and participated in the session on brain tumour support groups. Jean runs support group meetings for brain tumour patients and caregivers in Chicago

Dr Chengcheng Guo attended the IBTA Summit from the Sun Yat-Sen University Cancer Center in Guangzhou, China and participated in the workshop on brain tumour support groups

Sarah Rigby from the newly-established PVW Brain Tumor Foundation in Hong Kong

Bec Picone is the CEO and Founder of the Peace of Mind Foundation for brain tumour patients and families in Australia.

Concurrent Pick and Mix Session 4

Care Mapping for People Affected by Brain Tumours

Facilitators: Jelle de Vries, Executive Board Member, Hersenletsel.nl (The Netherlands) and Jenny Baker, Senior Advisor, International Brain Tumour Alliance (UK)

Presenter: Lena Davidsson, Chair, Swedish Brain Tumour Association (Sweden)

Lena Davidsson, Chair of the Swedish Brain Tumour Association, presented a workshop on care mapping

Rolf Ledal from Norway participated in the IBTA Summit workshop on care mapping. Rolf is the Secretary General of the Norwegian Brain Tumour Association.

THE Swedish Brain Tumour Association, Svenska hjärntumörföreningen, was founded in 2008 to support people in Sweden living with brain tumours. It has around 1,500 members, including patients and loved ones/caregivers. Among its many activities, the Association organises regional and national meetings, works to improve national care guidelines, and encourages research in prioritised areas. Its current chairperson is Lena Davidsson.

One fascinating study undertaken by the Association, in collaboration with the Regional Cancer Centre in Stockholm-Gotland and the Karolinska Institute, explores the use of care mapping as a tool for supporting people affected by brain tumours. The care and management of brain tumour patients is a complex issue involving many different people. Lena Davidsson said: "How can we from day one and all the way with the brain tumour, be better to see, appreciate and strengthen all relationships that are involved?"

About care mapping

As background to the care mapping workshop, Lena showed a pair of infographics by Sara Riggare, a Swedish Parkinson's patient, thought leader and entrepreneur. Each infographic displayed a year in the life of "Eva", a glioblastoma patient, shown as thousands of coloured dots. Each dot represented one hour of time: red dots = time spent in healthcare; yellow dots = time spent with social care; blue dots = time spent with self-care; and green dots = time spent with informal caregiving (with Eva's husband Wilmar).

The first infographic, depicting the first year of Eva's diagnosis, was dominated by blue dots (7,651 hours in self-care), followed by green (720 hours of Eva managing herself with the help of her husband), red (364 hours in healthcare) and yellow (30 hours of social care). The second infographic, depicting Eva's second year with a brain tumour, was dominated by green dots (3,750 hours) and red dots (2,880 hours). It was a stark portrayal of the dynamic relationships between patients, informal caregivers, community/social care and healthcare providers throughout a brain tumour journey.

"During life with a brain tumour, there are a lot of roles and perspectives that need to be integrated," Lena explained. Each stakeholder brings a different perspective at different times. It's essential to integrate, see, appreciate and strengthen all stakeholders if we want to improve outcomes."

Care mapping is a simple but highly effective way of depicting the complex web of relationships between patients, family, friends, caregivers, doctors and allied health professionals. By mapping out these relationships on a personal care map, the patient (or caregiver) can better understand their "care ecosystem"

Summit participant Yaron Butterfield from Canada created his own care map

Participants at the care mapping workshop had the opportunity to develop their own care maps

and perhaps identify areas needing attention, which can lead to improved care management and better outcomes.

Creating your own care map

Participants in this IBTA Summit session were given instructions on how to construct their own care map. Everyone was given a blank piece of A3 paper, a blue pen and a red pen. The care map starts by using the blue pen to draw yourself, and those living in your household, including pets, in the centre of the map. You are then asked to draw and label the people and communities outside of your household that you care about. Different shapes depict the different entities drawn, for example a circle for a person, a triangle for a pet, three circles for a community, and so on. Still using the blue pen, you are then asked to draw people and communities that care about you.

Arrows connecting you with each of these entities describe the type of relationship you have with them. Some arrows are two way, indicating that you care about someone and they also care about you. The arrows can depict the strength of the relationship, while numbers and symbols can be added to describe the importance and the frequency of the relationship.

Participants then switch to the red pen to draw in the people and communities that help you cope with your illness. Health and social care providers are drawn as a square. The resulting care map is a graphical representation of the complex web of relationships that make up your care ecosystem.

"The greatest insights come when you explain your care map to others," said Lena. "You can reflect on how the relationships feel today, and how they have changed over time. The lived experiences of how we feel, think and act in different situations are unique to us. Nothing is right or wrong when it comes to a care map," she added.

Summary

In summarising the session, Lena said:

- "We are now developing the tools of care mapping and doing different workshops where we learn how people experience the tool."
- "The goal is to create a tool that sees, appreciates and strengthens the relationships between the stakeholders on an individual level for a network affected by a brain tumour."
- "What can we learn from you?"

Concurrent Pick and Mix Session 5

Clinical Trial Endpoints in Neuro-Oncology

Facilitators: Nicole Willmarth, Chief Mission Officer, American Brain Tumor Association (US) and Dr Jing Wu, Investigator, NIH Lasker Clinical Research Scholar, Neuro-Oncology Branch, CCR, NCI, NIH (US)

Presenter: Lieutenant Colonel Brett Theeler, MD, Neurologist and Principal Investigator, Brain Tumor Trials Collaborative (BTTC); Lieutenant Colonel, Walter Reed National Military Medical Center (US)

Lieutenant Colonel Brett Theeler, MD (above right) presented at the IBTA World Summit on clinical trial endpoints in neuro-oncology. Dr Jing Wu (above left) and Nicole Willmarth facilitated the session.

Lieutenant Colonel Brett Theeler, MD

LIEUTENANT Colonel Brett Theeler, MD is Deputy Chief of the Department of Neurology at Walter Reed National Military Center in Bethesda, Maryland; Associate Professor of Neurology at the Uniformed Services University, and a Clinical Collaborator in the Neuro-Oncology Branch of the NCI.

Dr Theeler opened his breakaway session with an overview of endpoints and clinical trials. He explained the distinction between an endpoint and a surrogate endpoint. The definition of an endpoint is a "precisely defined variable intended to reflect an outcome of interest that is statistically analysed to address a particular research question." A surrogate endpoint is defined as "an endpoint that is used in clinical trials as a substitute for a direct measure of how a patient feels, functions, or survives."

Neuro-oncology clinical trials have traditionally used primary endpoints such as overall survival (OS), progression free survival (PFS) and overall response rate (ORR). A well-known example is the pivotal EORTC-NCIC phase III trial in newly diagnosed glioblastoma (Stupp R et al, 2005), where median OS was used to demonstrate the efficacy of radiotherapy plus temozolomide (14.6 months) over radiotherapy alone (12.1 months).

Clinical outcome assessments

Dr Theeler also stressed the importance of clinical outcome assessments (COAs) as endpoints in neuro-oncology clinical trials. These include:

- patient reported outcomes (PROs) – measurements based on reports coming directly from the patient
- observer reported outcomes (ObsROs) – measurements based on a report of observable signs, events or behaviours by someone other than the patient or health professional, typically a caregiver.
- performance outcomes (PerfOs) – measurements based on tasks performed by the patient in tests administered by a health professional, such as neuro-cognitive testing.

The EORTC-NCIC trial also introduced the concept of MGMT promoter methylation as a potential biomarker-associated

Nicole Willmarth, Chief Mission Officer, American Brain Tumor Association, was a co-chair of the clinical trials session at the IBTA Summit

surrogate endpoint. Patients with methylated MGMT promoter had a median OS of 18.2 months versus 12.2 months for patients with unmethylated MGMT.

Dr Theeler noted the difference between prognostic and predictive biomarkers. A prognostic biomarker is used to identify likelihood of a clinical event, disease recurrence, or progression in patients who have the disease or medical condition of interest. A predictive biomarker is used to identify individuals who are more likely than similar individuals without the biomarker to experience a favourable or unfavourable effect from exposure to a medical product or an environment agent. Biomarkers can also be diagnostic, for example, the IDH mutation in gliomas.

Surrogate endpoints

Care must be taken when using surrogate endpoints. In the phase II BRAIN study of bevacizumab in recurrent glioblastoma, the surrogate endpoint progression free survival at six months ("PFS6") was achieved in 42% (bevacizumab alone) to 50% (bevacizumab plus irinotecan) of patients. However, the subsequent phase III RTOG 0825 randomised trial of temozolomide plus bevacizumab in newly diagnosed glioblastoma showed no difference in OS between the bevacizumab and control arms, and only a small difference in PFS favouring the bevacizumab arm. This raises the question: "Did patients receiving bevacizumab clinically benefit?"

A further phase III study in recurrent glioblastoma which compared lomustine alone versus lomustine and bevacizumab also found that bevacizumab does not improve OS but does improve PFS. However, in quality of life measures, bevacizumab did not improve cognition or patient reported outcomes.

Despite a lack of an overall survival benefit and benefit as measured by PROs, treatment with bevacizumab results in a meaningful reduction in corticosteroid use. The FDA granted bevacizumab full approval for use in recurrent glioblastomas in 2017. Further study of PROs, ObsROs (observer-reported outcomes measures) and PerfOs (performance outcomes) in recurrent glioblastoma patients treated with bevacizumab are needed.

Questions and points from the floor

Session facilitators Nicole Willmarth and Dr Jing Wu opened the session to questions from the floor. Much of the discussion centred around new advances in clinical trial design and the use of biomarkers. A selection of topics discussed included:

- the use of imaging biomarkers, for example, MR spectroscopy for the detection of 2HG in IDH-mutant tumours – a very promising area of research
- the potential of liquid biopsy for diagnostic purposes or to monitor recurrence – need to overcome the problem of low sensitivity before it can be used in mainstream clinical practice
- phase 0 trials, where the patient is given a sub-therapeutic dose of the trial drug before surgery – can determine if the drug is actually reaching its target and whether the drugs do what they are expected to do before embarking on later phase trials
- using PRO-CTCAE (Patient Reported Outcomes – Common Terminology Criteria for Adverse Events) as one of the patient reported outcome measures
- SISAQOL – an international consortium (headed by the European Organisation for Research and Treatment of Cancer – EORTC) which aims to standardise the analysis and interpretation of patient reported outcomes and quality of life data in cancer clinical trials
- new clinical trial designs, such as basket trials (important for rare cancers with no standard of care beyond surgery and radiotherapy) or platform studies such as GBM AGILE

Concurrent Pick and Mix Session 6

Brain Tumour Registries

Facilitators: Carol Kruchko, President, Central Brain Tumor Registry of the US (US) and Ralph DeVitto, Chief Executive Officer, American Brain Tumor Association (US)

SESSION 6 of the Pick and Mix Sessions focused on brain tumor registries and was led by the American Brain Tumor Association (ABTA) President and CEO Ralph DeVitto and the Central Brain Tumor Registry of the United States (CBTRUS) President and Chief Mission Officer Carol Kruchko. The duo presented slides starting with a heartfelt dedication to Jennifer Gouchie-Terris and her son Brandon, who had successfully championed the establishment of the Brain Tumor Registry of Canada.

The Summit session on brain tumour registries was facilitated by Carol Kruchko and Ralph DeVitto

Ralph DeVitto, Chief Executive of the American Brain Tumor Association (ABTA)

Carol Kruchko of the Central Brain Tumor Registry of the United States (CBTRUS) is pictured above left with Liz Dawes of the RCD Foundation (above right)

After Ralph DeVitto emphasized the important role a dedicated brain tumor registry provides, especially in supporting research, Carol Kruchko outlined the goals of their presentation, which included describing the types of registries. These are: (1) population-based registry, which represents the entire population of a specific geographic area; (2) hospital-based registry, which represents patients in a specific healthcare facility or group of facilities; and (3) patient-based registries, such as those specific to a certain brain tumor histology or representative of patients enrolled in a clinical trial. She explained that CBTRUS is a population-based brain tumor registry and explained how CBTRUS started as an ABTA committee project almost thirty years ago.

Ms. Kruchko emphasized that there is more to a registry than just providing statistical information. It is important for the mission of the registry to ensure that the data collected are complete and accurate and reflect current clinical practices, such as the documentation of biomarker collection. It became clear that the Summit participants were interested in having a dedicated population-based brain tumor registry in their countries and the presentation changed course and moved away from following a prepared slide presentation.

Establishing a brain tumour registry

Ms. Kruchko referenced the steps she and her ABTA Committee had followed in establishing CBTRUS. Recommendations included:

- search population-based sources of cancer data in their home countries i.e. country cancer registry;
- search publications on the incidence of brain tumors in their countries;
- contact the author(s) of these publications and involve them in establishing a brain tumor registry; and
- find funding to support researcher efforts and for the development of a registry.

Ralph DeVitto elaborated on funding support, suggesting the cost for such studies would be approximately $60,000 and could be supported by grants. He emphasized the need for a dedicated advocate for funding and cautioned against launching a brain tumor registry without a plan to ensure its sustainability. ■

Concurrent Pick and Mix Session 7

Brain Tumour Symptom Burden and Management/Palliative Care

Facilitators: Christine Mungoshi, Director, Zimbabwe Brain Tumour Association, Helen Bulbeck, Founder and Director of Services and Policy, brainstrust (UK)

Presenter: Christine Siegel, Nurse Practitioner, NCI-CONNECT, Neuro-Oncology Branch, CCR, NCI, NIH (US)

The aims of this workshop were:

- to help Summit attendees feel less isolated, part of a community, resourced, supported, confident and involved
- to broaden and deepen understanding of the challenges that come with living with a brain tumour
- to develop strategies to help Summit attendees support their communities, so that their communities feel more resourced and resilient
- to provide some take away tools that people can use in their daily interactions with their communities

Presentation

Christine Siegel opened the workshop by sharing details of the symptom burden that comes with living with a brain tumour and how this burden is different from living with other types of cancer.

Symptoms of a brain tumour include: seizures, headaches, venous thromboembolism, focal deficits (mobility, vision), sleep-wake disruptions, mood disturbance (depression/anxiety; personality changes), and cognition changes/memory loss.

Christine then introduced the topic of palliative care and how this is supportive care, not necessarily end of life care. Coping techniques, mindfulness techniques, physical and occupational therapy should all have a role in palliative care to minimize symptom burden.

This breakaway session explored these themes. A round table discussion of what the attendees found most challenging when supporting their brain tumour communities took place. Responses fell into four categories:

Communication

- communicating the treatment options, or telling someone that treatment options have run out
- being asked by parents how to talk to their child who has a brain tumour and who is going to die
- Not knowing what to say
- talking about death
- how to respond to someone in denial
- Not knowing how to provide emotional support especially at end of life.
- explaining palliative care
- talking about the lack of time there is for the patient to do the things they want to do
- telling the patient that their situation is getting worse and there is not much the doctor can do
- anger with healthcare professionals for no cure, long time to diagnosis
- stigma around palliative care
- not wanting to raise the topic of palliative care
- difficult conversations
- moving away from the comfort zone

The role of the caregiver

- how to support a 24-year-old young man with a GBM and his family and friends
- how to meet the caregiver's additional physiological and emotional needs e.g.
  - accommodation
  - food, toiletries
  - loss of work/income
  - those at home e.g. siblings, children.
- never having a day off
- coping with grief when supporting someone on their own journey
- not doing enough to manage symptoms related to coping, mood disturbance
- not much attention for caregivers, never asking 'how are you?'

Impact on patient	The pathway
■ patient becomes slower ■ personality changes impacting on families and ability to be cared for at home ■ living with uncertainty ■ loss of identity 'I just don't feel the same.' How do I answer this?	■ how to donate a post-mortem brain to research ■ late referrals to palliative care ■ misunderstanding about the difference between end of life care (EOLC) and palliative care ■ thinking palliative care is not active care ■ anxiety about lack of health care access

Summit participants watch a presentation by Christine Siegel, Nurse Practitioner at NCI-CONNECT

The Summit workshop on brain tumour symptom burden and management/ palliative care was facilitated by Christine Mungoshi (above left) of the Zimbabwe Brain Tumour Association and Helen Bulbeck (right) of brainstrust

The group then focussed on how to address these challenges. Discussion centred on the notions that it is not necessary for everyone to be fixers, and that mostly people have the resources to sort problems themselves; they just don't know how.

Problem Outcome Framework:

The "problem outcome framework" is very useful as it enables people to think about how they are approaching a problem and enables them to think about what it is they want and how they might move forward. It's useful as a starting point.

The problem questions focus on the problem. The outcome questions are solution oriented, so focused on goals which is where energy should be placed. Decisions then become aligned as people know what their focus is. These questions are not focused on why the problem exists but what is wanted and how to achieve it.

Problem	Outcome
What problem do you want to explore?	What do you want to achieve in the next few months?
How long have you known about it?	What will help you to progress?
What has been hard?	Who can help you?
Who is to blame?	What skills or experience can you call upon from other parts of your life that will be useful to you here and now?
What is not going as you would wish?	What would be a good first step?

Participants used the framework to explore specific problems and recognized the difference between the two conversations. The group then explored how this could be used within the brain tumour context, with patients and with caregivers. With caregivers, feedback tends to be focused on the person as a caregiver. We explored how, as a caregiver, is it realistic for you to do anything for yourself, where and when we discount our own needs in service of others. We talked about the need for a caregiver sanctuary and what that sanctuary looks like. ■

Concurrent Pick and Mix Session 8

Brain tumour survivorship care planning and implementation

Facilitator: Maureen Daniels (Canada), Coordinator, The Gerry & Nancy Pencer Brain Tumor Centre, Princess Margaret Cancer Centre, Toronto, Ontario, Canada

Speaker: Dr Heather Leeper (US), Assistant Research Physician, Neuro-Oncology Branch, CCR, NCI, NIH

Dr Heather Leeper of the Neuro-Oncology Branch at the National Cancer Institute led a workshop on brain tumour survivorship care planning and implementation

Maureen Daniels facilitated the survivorship workshop

DR Leeper started this session with a discussion about what the phrase "cancer survivorship" could mean. "Survivorship" intends to describe the broad patient experience across the entire continuum of living with, through, and beyond a cancer diagnosis and treatment. She acknowledged that there is no mandate or obligation for patients to self-identify as a "survivor", though the term "cancer survivorship" is used by healthcare professionals to refer to the experience of being diagnosed and treated for a cancer diagnosis.

Dr Leeper provided a brief summary of what the American Society of Clinical Oncology (ASCO) and the American College of Surgeons' Commission on Cancer have recommended as components of cancer survivorship care plans. She followed this with a comprehensive and succinct presentation of the current version of the Neuro-Oncology Patient Survivorship Care Plan, developed by a multidisciplinary, interprofessional working group and endorsed by the Society for Neuro-Oncology (this plan is available as a free PDF download from the Society for Neuro-Oncology's website).

Background to the Neuro-Oncology Patient Survivorship Care Plan

Dr Leeper provided background on the reasons for the development of this tool. It gives patients and their healthcare providers a comprehensive summary of all the patient's cancer-related treatment, side effects, acute and long-term toxicities. It also might include follow-up imaging, hearing testing, details of referrals (ie to occupational therapists) and driving assessments. This helps facilitate communication between patients and their healthcare providers about developing an individualized plan for comprehensive, whole person care which addresses the unique needs and goals of each person.

Petra Hoogendoorn of Goings-On in The Netherlands

The need for such a tool was identified within the United States' healthcare system, which is highly fragmented. Such tools are now mandatory. Given that several cancer diagnoses, such as lung, breast, prostate, head and neck cancer, and lymphoma, have specific survivorship care plans tailored to the unique issues of their patient populations, the need for a neuro-oncology patient specific survivorship care plan was recognized. Such a plan could provide equitable survivorship care.

Goals and vision

Dr Leeper also discussed the goals of the tool and the vision for its use. Ideally, the Neuro-Oncology Patient Survivorship Care Plan should be piloted by neuro-oncology providers and patients to learn more about the survivorship issues. This includes how the care plan itself can be adapted, either in whole or in part, or revised to optimize care coordination, based on different healthcare systems. For survivorship care to be optimal, it needs to be addressed at the local level within the context of local resources, local language, customs and norms.

After Dr Leeper's presentation, the group enjoyed a lively discussion about the survivorship tool.

Key insights from session participants included:

- The document is currently very medically-focused and lengthy. Some healthcare systems allow patients to have increasingly easy access to their own medical records (via patient portals) which provide a great deal of information that is itemized in the current draft of the Neuro-Oncology Survivorship Care Plan. However, many healthcare systems do not have this facility, and even if they do, patients often receive care from more than one centre, leading to fractionization of their healthcare. Therefore, optimizing the care plan's content to that which is only essential and most useful was advised.
- Several participants observed that the current Neuro-Oncology Survivorship Care Plan lacks information in terms of patients' desired functional outcomes, spiritual, psychological and emotional needs and goals. Summit participants at this session expressed their strong recommendation that the document be adjusted to accommodate information about what an individual derives energy from, what they "need" to do (i.e. because of finances), or "want" to do (i.e. attend upcoming special events such as weddings, graduations, etc).
- There was also the suggestion that the document should be kept brief and simple due to limitations of healthcare systems/providers to create lengthy care plans and to facilitate updating. It was suggested that the patient-specific goals be no more than five to ten statements that could be completed at a number of healthcare provider visits, in order to record each patient's evolving experience of their "new normal".
- Several other practical issues where discussed, such as ensuring that the care plan is easy to read and comprehend. This could be done by seeking expert review by a reading specialist. Additionally, the group discussed whether pediatric neuro-oncologists would like to have their own version although the current version is designed to also accommodate pediatric patients. There was strong support for converting the care plan into electronic format for use within electronic medical records and as an App. This could facilitate its use/relevance within some healthcare systems and some patient demographics.

Plenary Session 5

Co-chairs: Catherine Hindson (Australia) and Melissa Lim (Singapore)

Brain Tumor Support Group – Indian Context

Presenter: Dr Nitin Garg, Consultant Neurosurgeon, Bansal Hospital, Bhopal, India, and Founding Director of BTSG (Brain Tumor Support Group and Awareness Foundation)

DR Nitin Garg is a Consultant Neurosurgeon in Bhopal, India, and also a founding director of BTSG (Brain Tumor Support Group and Awareness Foundation), the first patient advocacy group to be established in a private hospital in India.

Dr Garg presented an overview of brain tumour treatment and patient care in India. He said "The brain tumour community in India is an underserved population group. Neuro-oncologists have traditionally focused on improving therapeutic strategies. Psycho-

Consultant neurosurgeon Dr Nitin Garg from Bhopal, India, gave a presentation on the challenges of treating brain tumours in his country.

Dr Nitin Garg helped establish the newly-founded BTSG (Brain Tumor Support Group and Awareness Foundation) of Bhopal

social needs also need to be addressed in a structured manner."

He said that a recent study showed a five times greater incidence of brain tumours in developed countries in the West compared with low-to-middle income countries in the East, including India. Dr Garg suggested that this difference could partially be due to factors such as the environment, genetic susceptibility and demographics. However, issues such as delays in diagnosis, access to healthcare services and lack of documentation (registries) were also likely to contribute.

Life and cultural factors

According to Dr Garg, brain tumour patients in India experience a number of significant life disruptions following their diagnosis, including treatment, family dynamics, financial, career/education, emotions, peer relations, self-esteem, and future plans. Patient advocacy organisations and brain tumour support groups play an active role in addressing these issues by raising awareness, sharing information and providing support to patients and their caregivers.

Cultural factors are important. Dr Garg quoted Charaka, the Father of Ayurveda Indian Medicine, which represents a multidisciplinary and collaborative approach that many Indian clinicians practice:

"A physician who fails to enter the body of a patient with the lamp of knowledge and understanding can never treat diseases. He should first study all the factors, including environment, which influence a patient's disease, and then prescribe treatment…"

Challenges for Clinicians, Patients and Caregivers

Dr Garg explained that the treatment of brain tumour patients in India presents a number of challenges for clinicians. The primary contact for patients is still the neurosurgeon and communication between surgeon and patient can be difficult due to the surgeon's busy workload, social barriers and other reasons. Some patients have strong alternative beliefs and may prefer alternative medicine encompassed by "Ayush", an Indian system of care, including ayurveda, yoga, unani, siddha and homeopathy which can interfere with conventional therapies if used improperly.

Clinicians are also faced with a lack of standard criteria for neuro-oncology practice, variations in infrastructure and inadequate access to facilities. Responding to a question about how patients might overcome the taboo associated with cancer and seek psychiatric help, Dr Garg said: "If the treating oncologist refers the patient to the clinical psychologist, as part of a multi-disciplinary team, then it breaks the taboo."

Likewise, Indian patients are presented with a number of challenges when diagnosed with a brain tumour. Sometimes the treatment path is not straight forward and the patient is faced with a number of important decisions regarding possible treatment options. There may be delays in diagnosis and/or treatment, difficulty in obtaining second opinions, financial considerations and challenges finding social support. Changes in workplace, marriage and family relationships can introduce additional stresses, particularly in India's patriarchal family system. "Often in the decision-making process, family members take over and the patient is not given the power to decide." said Dr Garg. "However, a strong joint-family (multiple generations living under the same roof) support system can also be a good point," he acknowledged.

The caregivers of brain tumour patients face their own set of challenges which are often under-appreciated. Without a dedicated forum, caregivers lack the opportunity for open discussion with others. Stress can be caused by the fear of losing the loved one, conflicted views over treatment decisions, getting the treatment done, coping with the patient's medical issues and financial insecurity.

Indian Society of Neuro-Oncology Annual Congress

The Indian Society of Neuro-Oncology addresses many of these challenges at their Annual Congress called ISNOCON. In April 2019 ISNOCON was held in Bhopal, India. A major focus of this conference was multi-disciplinary collaboration. The conference attracted 350 delegates, including an international faculty of 13 specialists from Canada, US, UK, Germany and South Korea. IBTA Chair and Co-Director Kathy Oliver was one of the keynote speakers on the faculty. IBTA Co-Director Gordon Oliver also attended ISNOCON in Bhopal.

For the first time there was a dedicated session at ISNOCON on psycho-oncology. This was attended by brain tumour patients and their families. Patient groups such as the Brain Tumour Foundation of India (BTFI) and the IBTA were also active participants, and the session also marked the inauguration of the Brain Tumor Support Group of Bhopal.

Dr Garg summarised the take home messages from his session at the IBTA Summit:

1. multi-disciplinary team
- important for appropriate and prompt diagnosis and post-operative management

2. effective communication
- disease, treatment related, long term survivorship, recurrence;
- helps allay the fears experienced by both patients and caregivers

3. coping mechanisms
- how to reduce apprehension regarding tumour recurrence

4. social Integration
- workplace support, understanding colleagues significantly reduces stress levels

5. narrative medicine
- provides an emotional catharsis / someone to listen to
- platform to allow patients and care givers to express their pent-up feelings
- opportunity for the patient to voice fears, triumphs and hopes
- reduces the psychological burden. "One amongst others" and not "the only one"
- opportunity to share the difficult journey with others.

In concluding his presentation, Dr Garg introduced the BTSG (Brain Tumor Support Group and Awareness Foundation of Bhopal – www.btsgfoundation.in). "Brain tumour support groups created by patients and families are an immense source of strength and information to the newly diagnosed patients and their caregivers," he said. ■

Collaboration is the Key – Thinking outside of the box to create innovative partnerships

Presenter: Lisa Simms Booth, Former Senior Director of Patient and Public Engagement, Biden Cancer Initiative (US)

Lisa Simms Booth

Lisa Simms Booth has worked in patient advocacy for over fifteen years, most recently as Senior Director of Patient and Public Engagement at the Biden Cancer Initiative, where she helped define the organisation's advocacy outreach and partnership strategies. Lisa delivered a powerful and motivating presentation on collaboration and building innovative partnerships.

She noted that patient advocacy organisations are in a constant battle to get their message across, to raise awareness for their cause, to fundraise, or to simply engage with their supporters, volunteers and donors.

Lisa Simms Booth said: "We are so much more powerful together than we are alone. Collaboration is the key. How can you broaden that group of people that you work with, by thinking outside the box? You need a Call to Action which is a rallying cry to help mobilise people behind your cause. An example would be: 'Join us to halve the cancer rate'."

Lisa explained that initial responses will most likely come from hospitals, advocacy groups, and other groups which an organisation has previously engaged with. However they may also come from non-traditional sources, such as corporate bodies.

The Open Homes Initiative

"AirBnB is an example of a corporate who heard the call," said Lisa. After Hurricane Sandy hit New York in 2012, some AirBnB hosts opened their homes for free to neighbours who had been forced to evacuate. Inspired by their generosity, AirBnB started the Open Homes programme to connect people with a free place to stay in times of need.

The programme proved to be very successful and has expanded to offer free accommodation to people who need to

travel for medical treatment or caregivers needing respite. Having identified a wonderful opportunity to fill a critical need, AirBnB now partners with non-profit organisations such as Cancer Support Community, Bone Marrow & Cancer Foundation, and others, to connect with patients and caregivers.

Lisa described the Open Homes initiative as a non-traditional co-operation opportunity. She suggested that the challenges and needs faced by patients during their cancer journey offered the right time to look for these non-traditional opportunities. "The more we think about answering these needs, the more we can bridge these gaps, these unmet needs," Lisa said.

She encouraged delegates to ask themselves who else might do this - who can we bring in?

She said: "Reach out. Issue a challenge. All you can do is ask the question. Not asking is a missed opportunity – just go ask them! And don't forget to tell the personal stories which can be very powerful." ■

A No Cost/Low Cost Hospital-Based Support Programme for Pediatric Brain Tumour Patients and Their Families - a care model for developing countries

Presenter: Anita Granero, Founder and President, Oscar's Angels France and Oscar's Angels Italia

Oscar's Angels, operating in France and Italy, is a highly innovative volunteer programme for supporting families of children and teenagers with brain and spinal cord tumours, severe neurological problems and those in palliative care.

Anita Granero, founder of Oscar's Angels France and Oscar's Angels Italia

OSCAR'S Angels France and Oscar's Angels Italia train teams of specialised volunteers to provide care and support in the hospital to families of children and teenagers with brain and spinal cord tumours, severe neurological problems and those in palliative care. Their Founder/President, Anita Granero, explained how this highly innovative programme works and why it is recognised as one of the best collaborative models in pediatric healthcare.

The children, hospital teams, advocates/volunteers and parents come together to form a collaborative care experience. Anita explained that the Advocate Volunteer is regarded as a new member of the multi-disciplinary team (MDT). "The patient and family need this support while they are at the hospital," she said.

To explain the type of support provided by the Oscar's Angels volunteers, Anita showed a brief movie about the charity's work at the Children's Hospital of Toulouse, France. The video can be viewed on their website: http://www.oscarsangels.com/

The video showed Oscar's Angels volunteers providing support to patients and families immediately before and after surgery. It is clear that the families are comforted by the presence of the volunteers, who are on hand to keep them informed, provide comfort and reassurance, and answer any questions.

It is also clear that the hospital staff - from the clinicians to operating theatre nurses - are very supportive and highly appreciative of the volunteers' work. The information and support they provide to the patients and families makes everyone's job easier and they are clearly regarded as part of the MDT team. "We

tailor the intervention to the needs of the families. Sometimes we will be with them for five minutes, sometimes an hour," said Anita.

The intense nature of the job can also take its toll on the volunteers and Anita said there are measures in place to cope with stress and prevent burnout. She said: "We talk. We have a debrief, on arrival and afterwards. The clinical team also talks to us, especially the nurses but also the surgeons and the neuro-oncologists. There is a psychologist available to the volunteers. Because we talk so much, everything is diffused immediately."

Asked how Oscar's Angels manages to source and maintain their volunteers, Anita replied: "Volunteers come from every walk of life. They might volunteer their time once per week, working in all areas from treatment to palliative care to end-of-life. It takes about a year of training before they can circulate in the hospital and tutor the junior volunteers. We explain the role to them clearly from the start. Selection is very important. Out of every ten applicants only three will make it as volunteers."

The willingness of hospital management and the health professionals to accept and support the volunteers as part of the team is crucial to the success of the programme, explained Anita. The other keys to its success include health professional's specific training, being a qualified charity, and having carefully selected, trained volunteers.

The volunteers' selection and training is a multi-stage process which takes over six months from first contact to final selection and training. Anita says that high-quality training and supervision is vital to the success of the programme. She said: "The advantages of this collaborative care model can be seen in the improved level of information and hospitality, better management of complex situations, and the humanisation of family care. The programme is cost effective – because it's free." ■

Plenary Session 6

Chair: Mary Ellen Maher, RN, APN, CNRN, Northwestern Medicine (US)

IBTA Senior Advisor Mary Ellen Maher chaired plenary session 6 at the fourth biennial IBTA World Summit of Brain Tumour Patient Advocates

The Brain Tumour Journey in Poland

Presenter: Magdalena Magiera, Chair and Co-Founder of Glioma-Center Foundation (Poland)

MAGDA Magiera co-founded the Polish brain tumour charity Glioma-Center Foundation with her husband in 2019, following the death of their daughter, Hania (Hanna), from a diffuse intrinsic pontine glioma (DIPG). The foundation advocates for better treatments for Polish glioma patients, including molecular diagnostics and innovative medicines. Magda gave delegates an overview of the brain tumour journey in Poland and how her Foundation is trying to change things for the better.

With a population of 38,496,000 Poland is the sixth most populous country in the European Union. Over 160,000 people are diagnosed with cancer each year, forecasted to grow by 2% by 2025, and there are over 100,000 cancer deaths each year. Brain tumours are relatively rare with approximately 3,000 people diagnosed each year, representing around 2% of all cancers. About 65% of brain tumours diagnosed are gliomas, and less than 1,000 are glioblastomas (GBM).

Magda Magiera, founder of the Polish brain tumour charity Glioma-Center Foundation

Cancer Treatment – Key Challenges

Magda explained that the survival rates for brain cancer in Poland are worse than the average survival rates in other European countries. She cited some possible reasons for this being late diagnosis, insufficient funding for research and treatments and inefficient prevention.
The standard treatment for malignant gliomas incudes surgery, radiotherapy with temozolomide, and adjuvant temozolomide (or other chemotherapy). Reirradiation is sometimes given on recurrence.
The standard treatment for children with gliomas consists of surgery (if possible), chemotherapy (two cycles), radiotherapy and adjuvant temozolomide or other chemotherapy.

Magda explained that brain tumour patients in Poland are faced with several challenges. Detailed molecular analysis is not part of the standard treatment. Some centres do very basic molecular testing, such as IDH mutation or MGMT methylation, however often there are no treatment recommendations arising from the molecular report. Generally, a personalised treatment approach is not applied, and there are very few clinical trials available to brain tumour patients in Poland.

Kristen Gillette of The Kortney Rose Foundation in the United States congratulated Magda Magiera on her work in Poland for brain tumour patients and their families

Glioma Center Foundation – A Family's Journey

The inspiration behind the formation of the Glioma-Center Foundation is Magda's daughter, Hanna, who passed away in October 2018. After Hanna's diagnosis with DIPG in April 2017, the family found a lack of effective treatment options in Poland so began to search for innovative and experimental treatments abroad. This led to a number of ground-breaking firsts, including Hanna's tumour being the first frozen DIPG tissue in Poland to undergo full molecular analysis in the United States. Hanna was the first European child on a CED (convection enhanced delivery) clinical trial at Memorial Sloan Kettering Cancer Center in New York, in which the therapy is delivered through a catheter inserted into the tumour. Later she also tried the experimental drug ONC201.
It was the extensive knowledge gained during Hanna's journey which motivated Magda and her husband to form the Hania Magiera Glioma-Center Foundation. The Foundation is set up to assist both adult and pediatric patients with malignant gliomas. They currently have three main areas of interest and action plans:

1. availability of molecular diagnostics in Poland – current obstacles are linked to lack of financial resources and lack of awareness among medical professionals and patients.
- advocate for increased resources from the public sector
- create a special fund sourced from the private sector
- carry out an awareness raising campaign

2. treatment options linked with tumour specifics – currently there is a lack of knowledge about possible treatment options
- develop a scientific programme with oncologists which links the patient's tumour molecular profile with possible treatment options

3. availability of innovative medicines – currently there are promising medicines which are not available due to incomplete registration process or trials still in progress
- advocate for wider compassionate use of relevant medicines.

In summary

Magda concluded her presentation by stating the Foundation's

over-riding broad objective – to focus on, and support, every person diagnosed with a glioma in Poland.

The passion and motivation demonstrated in Magda's telling of her personal story behind her Foundation certainly struck a chord with many people in the audience. Kristen Gillette, Founder and Executive Director of The Kortney Rose Foundation in the United States, stood to congratulate Magda on her presentation.

Kristen said: "I also lost my daughter to a DIPG. I commend you on your courage and thank you for sharing your story." ■

AIMING HIGH – The AIM BRAIN PROject in Australia: developing an Australasian diagnostic platform for molecular profiling of pediatric central nervous system tumours

Presenter: Liz Dawes, CEO and Founder, Robert Connor Dawes Foundation (Australia)

Liz Dawes of the Robert Connor Dawes (RCD) Foundation

"Aeternum Fortis", Latin for "Eternal Strength", was a mantra for the Dawes family during Connor Dawes' battle with anaplastic ependymoma. It was in this spirit that Connor's mother, Liz, founded the Robert Connor Dawes (RCD) Foundation following her son's death in April 2013. The Foundation has since grown into the largest pediatric brain cancer charity in Australia, raising to date over AUD 6.4 million in research funds. Liz shared the story behind the Foundation's formation and outlined one of its major initiatives – the AIM BRAIN PROject.

The RCD Foundation is a charity in two countries. It began as a 501(c)(3) non-profit corporation in the United States, Connor's country of birth, and then launched in Australia where Connor lived most of his life. The Foundation chose to concentrate on pediatric brain tumours and decided from the outset to adopt a collaborative mindset. "We decided to back the race, not the horse," Liz said.

The Foundation's major annual fundraising event is "Connor's Run", a fun run which traces the route of one of Connor's training runs in his home city of Melbourne, Australia. The 2019 Connor's Run attracted over 5,000 participants and raised an impressive A$1.2 million for pediatric brain cancer research.

Identifying key issues

Following the launch of the RCD Foundation, the key issues confronting the pediatric brain cancer community were identified. In the last 20 to 30 years there has been negligible improvement in the survival rate of pediatric CNS tumour patients and standard therapies still cause life-long, severe side effects for patients. However, much progress has been made in understanding the underlying biology of pediatric brain tumours. Tumours once regarded as single entities have now been shown to include multiple subgroups.

Some of the most significant advances in this area have been made at the German Cancer Research Center (DKFZ) in Heidelberg under their Molecular NeuroPathology 2.0 Study (MNP2.0). Researchers use whole genome methylation profiling to produce a "methylation fingerprint" of the tumour. The additional information provided by this type of molecular profiling offers the best chance of finding the most effective treatment options.

Determined to have this technology available in Australia, the RCD Foundation joined with the Australia New Zealand Children's Haematology and Oncology Group (ANZCHOG) to initially have the

MNP2.0 study opened to children in Australia and New Zealand, before commencing a molecular profiling project in Australia.

The AIM BRAIN PROject

The resulting AIM BRAIN PROject was set up to ensure that every pediatric brain cancer patient in Australia and New Zealand has access to advanced molecular profiling technology to enable an accurate diagnosis and to guide treatment options. The project is now fully funded to the tune of A$2 million, thanks to A$500,000 each from the RCD Foundation and Carrie's Beanies 4 Brain Cancer and an A$1 million grant from the Australian government.

There are eleven study sites in nine hospitals in Australia and two in New Zealand. Tumour tissue and blood samples are taken at the local treating hospital and sent to Germany (MNP2.0) and/or Melbourne (AIM BRAIN) for molecular profiling. Local pathology is compared with both the MNP2.0 molecular results and AIM BRAIN molecular results (patients can be co-enrolled in both MNP2.0 and AIM BRAIN). Validation of the AIM BRAIN methylation profiling is on track. Of 33 patients co-enrolled in both MNP2.0 and AIM BRAIN, 32 cases (97%) were concordant with the one non-concordant case subject to further review.

As of July 2019, 158 participants had been recruited to MNP2.0 and 72 participants to AIM BRAIN, with 47 co-enrolments. Early data from MNP2.0 shows that the study is already influencing patient care. For example, in 15% of patients the molecular analysis resulted in a change of diagnosis and subsequent change in treatment. "It is making a significant clinical impact," Liz said. ■

The CERN Foundation - a model of collaboration between the academic community and the patient advocacy community

Presenter: Kim Wallgren, President, CERN Foundation (US)

Kim Wallgren presented at the IBTA Summit on the CERN Foundation (Collaborative Ependymoma Research Network) of which she is President

Established in 2006, the CERN Foundation – Collaborative Ependymoma Research Network – is dedicated to improving the lives of children and adults worldwide who are diagnosed with ependymoma. Kim Wallgren has been with the CERN Foundation since its inception and has been its President since 2015. Kim revealed to the IBTA Summit participants her personal connection with ependymoma and the motivation behind her work with the Foundation.

Brain tumours have touched Kim's family more than once. Several years ago, her mother's first husband passed away from a GBM. Then, in 2002, tragedy struck when her father was diagnosed with an anaplastic ependymoma. Kim's father faced great hardship in dealing with his disease, as did her mother as his primary caregiver. They were helped greatly by seeking a second opinion at M.D. Anderson Cancer Center from Dr Mark Gilbert. It was 18 months after his last treatment that her father managed to tell his first joke.

In 2006, Kim's father suffered a recurrence of his brain tumour and the family was faced with a new set of challenges. It was not long after this that the CERN Foundation was born, offering a new sense of hope and optimism for Kim and her family. "The diagnosis did not change, the outcome did not change, but we changed," she said.

Kim was motivated to help with the newly formed Foundation in any way she could. She was grateful that they allowed her to participate and to help them accomplish their goals. Recalling her emotions at the time, she said: "Somebody out there cared, and somebody out there was going to do something about it."

Collaboration is part of the CERN name and is at the heart of everything they do.

The CERN collaborative model

Kim said: "One of the most unique aspects of the CERN Foundation is that it creates space for genuine partnership between the patient and scientific community and that interaction and spirit of collaboration continues to impact the field of neuro-oncology in significant ways."

Kim described the collaborative model and how it applies to their work with researchers and clinicians. The CERN Foundation has five main collaborative research areas:

1. Clinical Trials

- Clinical trials are the vehicle by which the CERN collaborative team brings advances in understanding of ependymoma biology and treatment directly to patients.

- Parallel trials for both children and adults with ependymoma

2. Tumour Profiling and Pathology

- Integrating histology and molecular biology to improve the accuracy of ependymoma diagnosis and prognosis
- Develop the new tools to create new assays to study patients undergoing treatment in clinical trials

3. Developmental Therapeutics

- Using state-of-the-art, industry standard approaches to screen thousands of novel compounds and known drugs as possible new treatments for ependymoma
- Test these agents in new disease models to advance to clinical trials

4. Tumour Stem Cell and Laboratory Models

- Studying normal and malignant development in the brain to uncover the cellular and molecular origins of ependymoma
- Develop laboratory models of ependymoma to test potential new treatments for clinical trial

5. Patient Outcomes

- Exploring ependymoma epidemiology and impact of the tumour and its treatment on patient function and quality of life
- Provide insights into the design of CERN clinical trials including the impact of the treatment on the patient

Kim shared her keys to successful collaboration between academia and patient advocacy. "Invest in relationships, don't put limitations on these. Engage in communication, seek inclusion, especially with voices that are unheard, and recognise the value in others," she said. In concluding, Kim offered delegates an alternative definition of hope:

"Hold On to Possibilities that are Extraordinary – HOPE." ■

Living Through and Learning From a Brain Tumour Diagnosis

Presenter: Dr Neil Bindemann, Executive Director, Primary Care and Community Neurology Society (UK)

Dr Neil Bindemann is a brain tumour survivor. He shared his thoughts with the IBTA World Summit participants about living through and learning from a brain tumour diagnosis

DR Neil Bindemann is trained in both immunology and neurobiology and has a keen interest in the developing science of neuro-immunology, especially concerning mental health. He is also a brain tumour survivor, having been diagnosed with a rare pineocytoma in 2015. Dr Bindemann shared his unique perspective on being diagnosed with a brain tumour.

Dr Bindemann set the tone of his presentation by emphasising that he much prefers the phrase "living through a brain tumour", over "living with a brain tumour." "If you're living with it, it holds you back. If you're living through it, there's light at the end of the tunnel," he said.

Trauma

Dr Bindemann began by citing a dictionary definition of "trauma" as "a deeply distressing or disturbing experience." However, he qualified that definition by adding that "deeply" is not a good word to use because it is subjective. "A low grade brain tumour can be a high grade trauma," he suggested.

An alternative, medical definition for "trauma" is "an incident that results in a combination of mental and physical manifestations," he added.

Probing further into the concept of trauma, Dr Bindemann referred to the book "The Molecules of Emotion" by neuroscientist Dr Candace Pert. Building on her concept that "the mind and the body are one", he suggested that our mind-body functions as a flow of information between our nervous system, our endocrine system, our immune system, and our gut.

He suggested that trauma can interrupt the information flow of this whole system. "Physical trauma disrupts the flow from the outside in. Mental trauma disrupts it from the inside out," he explained.

A dictionary definition for "post-traumatic stress disorder" is "a condition of persistent mental and emotional stress occurring as a result of injury or severe psychological shock."

In Dr Bindemann's model, the body and the mind come together when it comes to trauma. His personal experience involving the mental trauma of a brain tumour diagnosis and the physical trauma of brain surgery have given him a different perspective on this, he said.

So how do we limit the mental health impact caused by trauma?

Dr Bindemann explained that the first step is recognising the trauma. It didn't matter whether the tumour was malignant or non-malignant, there was still the physical trauma of an operation. He described how he felt at the time of his diagnosis. "The trauma of the body had already been going on. The trauma to the mind was going through the roof!"

On his discharge from hospital following surgery, he was moved out of a secure hospital environment, where specialist care had been available 24/7, to a sense of relative isolation at home. At this point, Dr Bindemann believed that access to a community rehabilitation service was desperately needed. "All patients should be offered a needs assessment," he said. "This can help stop issues such as depression, not just with the patient, but the whole family."

When asked if primary care professionals should be part of the care group, Dr Bindemann replied: "In the UK, primary care is changing. Primary care networks are being formed. It's no longer just the general practitioner (GP), but other allied health professionals are now involved. The primary contact person might be a physiotherapist, for example. It needs a dedicated community approach."

Co-ordinate care in the community:

- Preparation for hospital discharge – help set expectations
- Communication between hospital discharge and community-based teams
- All patients and families should be offered a needs assessment
- Signposting to support services for all patients should be routine
- Agreement on who is responsible for the ongoing mental health support for the patient and family members
- Contact with patient and family within an agreed time frame, once home
- Information for patients/families on how and where to access support

Dr Bindemann concluded his presentation by defining his hopes for the future: "My wish? Help people and families live through their brain tumour experience and give them back their purpose in life." ■

Day Three: Saturday 12 October 2019

Hyatt Regency Hotel, Bethesda, Maryland, US

THE final day of the IBTA World Summit of Brain Tumour Patient Advocates was held at the Hyatt Regency Hotel, Bethesda, Maryland. The programme consisted of four plenary sessions, with the final three sessions being expert panel/audience discussions.

Participants at the IBTA World Summit assemble for the final day of the conference which was held at the Hyatt Regency Hotel in Bethesda, Maryland

Plenary Session 7

Chair: Gordon Oliver, Co-Director, International Brain Tumour Alliance (UK)

IBTA Co-Chair Gordon Oliver introduces plenary session 7

How To Get The Best Out of Your Policy Work

Presenter: David Arons, JD, CEO, National Brain Tumor Society (NBTS, US)

National Brain Tumor Society's Chief Executive Officer David Arons presented at the IBTA Summit on getting the best out of policy work

DAVID gave delegates an introduction to NBTS before sharing his thoughts and ideas on public policy for brain tumour advocates.

NBTS was formed as a result of the merger in 2008 of the US Brain Tumor Society and the US National Brain Tumor Foundation, with an overall combined history in excess of 30 years.

"NBTS has a vision to conquer brain tumours, not just cure brain tumours," David explained.

He added that funding research is a very important part of the NBTS strategy, both in terms of directly funding grants itself and participating in research collaboratives. He also outlined some of the Society's patient and caregiver resources available on their website. These include "The Brain Tumour Experience", a coaching and information guide for patients and caregivers, and the "NBTS Clinical Trial Finder" which helps patients connect to relevant clinical trials.

NBTS is a leader in the public policy area of brain tumour advocacy. David described their strategy as "The Four Pillars of Policy Work":

Policy Frame: It's crucial to ask if public policy change can actually solve the problem. In other words, "Does government have the authority to solve the problem? If so, are they capable of making the necessary change?" he asked. The next step is to develop the policy solution. This requires a positive effect on the problem, the support of the policymakers' constituency, and credibility.

Relationships: "Build relationships with those who can directly or indirectly support your proposal," said David. He described three key relationships as 1) government, 2) people (citizens, coalitions, stakeholders), and 3) media.

Program Design: David framed his key elements of Advocacy Program Design into three "C's": **choreography** – you need to map out a clear strategy; **cadence** – the effort must be co-ordinated; and **communications** – stories: tell people why this issue is important to you. "Stories bring the human element," said David.

The Childhood Cancer STAR Act – A Case Study

The Childhood Cancer STAR (survivorship, treatment, access and research) Act was signed into law in the United States in 2018. It is the most comprehensive childhood cancer legislation passed by the US Congress in decades. The Act is designed to advance pediatric cancer research and treatments, improve childhood cancer surveillance, and provide resources for survivors and those impacted by childhood cancers.

Brain tumours are the leading cause of cancer-related death in children and NBTS played a major role in championing the bill from its inception, directly contributing to its content and helping push it through the legislative process. David put the success of the STAR Act down to clear problem, clear solution, clear beneficiaries (parents, children, researchers), emotional stories, and government, citizen and media support.

In conclusion, David shared three tips for public policy advocacy work: (1) "Be patient – change doesn't happen quickly. (2) Be willing to compromise your ask, not your credibility, mission or reputation. (3) Be willing to work with others you haven't worked with in the past," he said. ■

All.Can international Patient Survey Update

Presenter: Suzanne Wait, Co-Founder and Managing Director, The Health Policy Partnership (UK) on behalf of All.Can international

ALL.CAN is an international multi-stakeholder not-for-profit initiative. Its goal is to improve the efficiency of cancer care by focusing on what matters most to patients. All.Can membership comprises leading representatives from patient organisations, policymakers, healthcare professionals, research and industry. The International Brain Tumour Alliance sits on the Steering Committee of All.Can and has been involved with the initiative from its beginnings. Suzanne Wait, Managing Director of The Health Policy Partnership (HPP) which provides the Secretariat of All.Can international, presented an update on their international patient survey.

Dr Wait explained that the patient perspective is often overlooked in considerations of how cancer care can be improved. The All.Can survey presented a unique opportunity to ask patients and caregivers directly about their experience with cancer, and where they thought there were inefficiencies with their care. Inefficiency is defined by All.Can as "the allocation of resources to anything that does not focus on what matters to patients." Almost 4,000 people from over ten countries across the world responded to the survey and the findings are presented in a report titled: **"Patient insights on cancer care: opportunities for improving efficiency"** (https://www.all-can.org/what-we-do/research/patient-survey/)

The survey covered all cancer types, not only brain and CNS tumours. It was acknowledged that, while all cancer patients undergo a different experience with their disease pathway, there are many areas of treatment and care where common inefficiencies occur. For logistical reasons, the survey was only opened to certain countries.

What opportunities for improving cancer has the survey identified?

Four main opportunities to improve cancer care efficiency were identified in the survey results:

1. **Diagnosis**
   - Diagnosis needs to be faster, more accurate, and appropriately delivered.
   - Delayed diagnosis was more common in younger patients.
2. **Better information at all stages of care**
   - Respondents said they wanted not necessarily more information, but better information, at appropriate points along the care pathway.
3. **Integrated, multidisciplinary care**
   - Respondents felt that there was fragmentation and a lack of coordination in their care, especially between their general practitioner (GP) and specialists.
   - Psychological support was often not available and in some cases not appropriate. This indicates that there is a shortage of trained psycho-oncologists.
4. **The financial impact of cancer**
   - Respondents spoke not just of the costs of care and treatment but of the running costs of cancer, such as the cost of travel to medical appointments, childcare or household help, lost income from employment, and difficulties getting insurance, loans or mortgages after their cancer diagnosis.

Suzanne Wait from The Health Policy Partnership – secretariat for All.Can – presented on All.Can's international patient survey on inefficiency in cancer care

The importance of the All.Can cancer patient survey findings

Dr Wait provided some data from the literature underlying the importance of these findings.

- Late diagnosis and misdiagnosis can lead to delays in treatment or limited treatment options, poorer outcomes, lower likelihood of survival and higher costs of care.
- Fulfilling patients' needs for information is associated with improved treatment adherence and better clinical outcomes.
- Having a cancer nurse specialist in the UK has been shown to improve outcomes for patients and reduce the overall costs of care by 10%.
- Cancer patients with depression have a 39% higher risk of mortality and higher healthcare expenditure than patients who do not have depression.
- People surviving cancer are 1.4 times more likely to be unemployed and three times more likely to receive disability benefits than the general population.
- A study of working age cancer survivors in the United States found that one third had gone into debt, and 55% incurred costs of $10,000 or more due to their cancer.

Dr Wait said that the survey findings should be considered as evidence that can be used to guide policy making. The patient perspective should always be central to the development of integrated health and social policies. ■

Editor's Note: Since April 2020, All.Can has become a non-profit organisation based in Belgium.

Plenary Session 8

Moderator: Chris Tse, Senior Advisor, International Brain Tumour Alliance (New Zealand)

Chris Tse, IBTA Senior Advisor from New Zealand, moderated plenary session 8 on day 3 of the IBTA World Summit

Influencing the brain tumour research agenda and aligning perspectives on clinical benefit

Panellists: Yanfang Liu (Medical Director, Bristol-Myers Squibb, US); Susan Marshall (Chief Executive, Brain Tumour Foundation of Canada); Brock Greene (President, OligoNation, US); Terri Armstrong (Deputy Chief, Neuro-Oncology Branch, CCR, NCI, NIH, US)

This was the first of three panel discussions at the IBTA Summit. Panels were selected to represent a variety of perspectives on various topics, with the hope that the diverse viewpoints would result in an exchange of ideas, increased understanding, and opportunities for collaboration. Each panel member was given five minutes to present on the topic.
The moderator for this first panel discussion, Chris Tse, introduced the topic. Chris noted that brain tumour patient groups around the world had long been very vocal in calling for more research funding for brain tumours and recently their efforts had begun to bear fruit. However, raising funds is only the first step. Where the funds are directed and how they are utilised is equally as important.

Yanfang Liu

Dr Yanfang Liu is a medical director in the oncology clinical development team at Bristol-Myers Squibb (BMS). Dr Liu said that BMS has been active in all stages of medical research across multiple therapeutic areas, including brain and CNS tumours. BMS adopts a collaborative research approach, conducting some studies directly while also working with clinical investigators and research institutions in other trials.

BMS also conducts research into tumour biomarkers, including biomarker-driven clinical trials in both CNS and non-CNS cancers, on the understanding that increased knowledge of tumour biology will ultimately lead to more effective treatments. "In the case of rare tumour types, it is often not possible to conduct a large, randomised clinical trial," said Dr Liu. She said it is therefore important to identify certain cohorts within larger trials which may be showing strong clinical benefit.

BMS recognises that their research must be mutually beneficial for the patients and the company. Patient reported outcomes are a standard endpoint in all of their clinical trials.

Dr Yanfang Liu (second from left) from Bristol-Myers Squibb (BMS)

Susan Marshall

Susan Marshall, CEO, Brain Tumour Foundation of Canada spoke about representing the patient voice in brain tumour research. BTFC is the only national charity offering information and support to brain tumour patients in Canada. Their vision is to find the cause of and a cure for brain tumours while improving quality of life for those affected. Recognising that research is the key to completing this vision, Brain Tumour Foundation of Canada regularly awards grants to researchers and brain tumour research projects in Canada and through the Brain Tumor Funders' Collaborative. The Foundation does not directly fund clinical trial research, but their research programme does focus on outcomes which are meaningful and relevant to brain tumour patients. "BTFC funded research influences clinical outcomes," said Susan.

An area of focus for BTFC research funding is the career development of Canada's young scientists and clinicians. Every

Susan Marshall, (on stage, third from left), CEO of Brain Tumour Foundation of Canada

year they award fellowships and studentships providing funding to young Canadian researchers, helping to accelerate their careers in brain tumour research. Projects funded include basic scientific research through to quality of life studies.

BTFC is proud to represent the patient voice in brain tumour research in Canada. For example, they have collaborated closely with Clinical Trials Ontario in defining patient outcomes in brain tumour clinical trials. BTFC is also involved in research which addresses the inequalities in accessing chemotherapy drugs across Canada.

Brock Greene

Brock Greene was thrust into the realm of brain tumour patient advocacy following the diagnoses of both of his sons with oligodendrogliomas. After failing to find any organisations willing to fund research specifically into oligodendroglioma he launched Oligo Nation in 2014.

"Sometimes there isn't a research agenda," Brock said.

Since its formation, Oligo Nation has awarded 18 grants to innovative research projects focused on oligodendrogliomas. The emphasis is on translational research that can make a difference for survivors in the next three to five years. A major initiative is the establishment of an oligodendroglioma biobank which is used to build cell lines for important pre-clinical research.

Brock offered delegates a practical road map for funding brain tumour research: 1) **Get Educated** - you have to get educated so you can ask the right questions; 2) **Build a Team** - including advisors, oncologists; 3) **Money makes the world go round** - medical research takes money so having the money to invest is critical; 4) You have to **be impatient**; 5) **Don't reinvent** - there is an opportunity to leverage discoveries and new therapies developed for other forms of cancer and adapt it to our disease.

Brock Greene (far right) of OligoNation

Terri Armstrong

The final panellist in this session, Dr Terri Armstrong, was able to tie the discussion together by focusing on what is meaningful for patients. This is one of the overriding themes in her work as head of Patient Outcomes at the Neuro-Oncology Branch and as co-director of NCI-CONNECT.

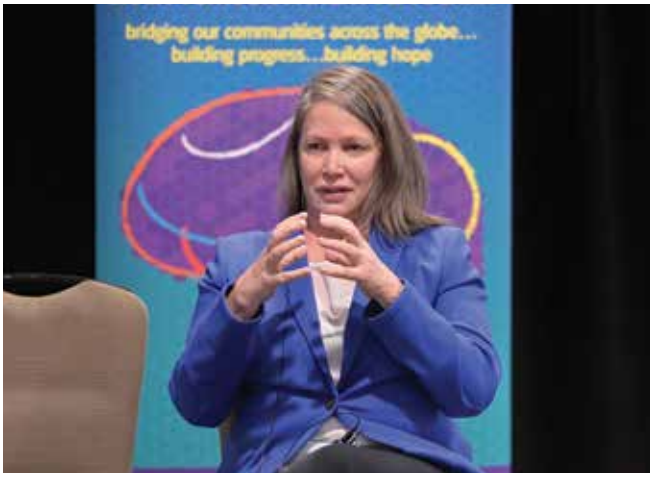
Dr Armstrong spoke of the Dr Seuss classic children's book "Horton Hears the Who" which contains the well-known phrase "a person's a person, no matter how small." This message could be applied to brain tumours in general, which by definition are classed as rare cancers, including the 12 rare CNS tumour types currently covered under the NCI-CONNECT programme.

Patient reported outcomes (PROs) in clinical trial research enable us to measure the true impact that a treatment can have on the patient, in ways which are truly meaningful to them, said Dr Armstrong.

A meaningful impact for patients may not simply mean increasing overall survival. Meaningful impact could be living better as opposed to living longer.

By stopping the tumour from growing, and keeping the patient feeling better for longer, we can make a meaningful impact on their life.

The impact on patients can be great. Over 50% of low and high grade tumour patients have difficulty returning to work. Symptoms which start at the time of diagnosis can continue throughout the time the person is dealing with the illness. ■



Dr Terri Armstrong of the NCI's Neuro-Oncology Branch and Co-Director of NCI-CONNECT

Plenary Session 9

Moderator: Rosemary Cashman, IBTA Senior Advisor and nurse practitioner at the BC Cancer-Vancouver Centre (Canada)

Improving accrual to brain tumour clinical trials

Panellists: Amanda Bates (Assistant Director of Community Relations, National Brain Tumor Society/NBTS, US); Kay Verble (CEO Sontag Foundation, US); Marta Penas-Prado (Neuro-Oncologist, Neuro-Oncology Branch, CCR, NCI, NIH, US); Ely Benaim (Chief Medical Officer, Novocure, US); Kathleen Wall (Clinical Research Nurse, NCI-CONNECT, NOB, CCR, NCI, NIH, US)

Dr Marta Penas-Prado

Karen Risgaard of the Danish Brain Tumour Association, makes a point during plenary session 9

IBTA Senior Advisor Rosie Cashman, nurse practitioner at the BC Cancer-Vancouver Centre in Canada, moderated plenary session 9

Irene Azong-Wara, founder of Jacob's Hope Foundation in Cameroon, highlights challenges for brain tumour patients in sub-Saharan Africa

Yaron Butterfield, a 15-year glioblastoma survivor puts a question to the panel in plenary session 9

Danielle Leach from the National Brain Tumor Society in the United States

Amanda Bates

Amanda Bates opened the second panel discussion by outlining some of the key findings from the NBTS 2016 Patient and Caregiver Clinical Trial Survey. This online survey aimed to determine the level of knowledge, experience, and perceptions of brain tumour patients and caregivers with respect to education and participation in clinical trials. The survey revealed that only 42% of patients were informed about clinical trials by their medical team and 36% of patients never discussed clinical trials with their doctors.

She explained that the top three reasons for patients to participate in clinical trials (according to the NBTS survey) were:

- The patient felt that it would not only help them but also help future brain tumour patients.
- The patient felt their chances of survival seemed better with the proposed experimental treatment.
- The patient felt the potential benefits outweighed the risks of clinical trial.

The top three reasons for patients not to participate in clinical trials were:

- The patient's doctor did not recommend participating in the clinical trial.
- The patient did not qualify for the clinical trial.
- The patient and caregiver did not know where to find a clinical trial.

The survey highlighted the urgent need for increased patient awareness of clinical trials.

Amanda also noted that the role of clinical trial nurses to explain the research studies to patients is vital.

Kay Verble

Kay Verble, Executive Director of the Sontag Foundation and a Director at Brain Tumor Network (BTN) continued the discussion. Kay said that to improve accrual to brain tumour clinical trials we need to know more about a) the patients who want or need clinical trials, and b) the barriers they encounter or perceive.

At Brain Tumor Network, which assists brain tumour patients in navigating the health system in the United States, one third of patients seeking navigation services enquired about clinical trials. Of the patients seeking trials, 90% had high grade glioma (37% newly diagnosed, 63% recurrent) with the remaining 10% having other tumour types.

The reasons patients reported for not enrolling in a clinical trial were: trial location (36%); financial burden (31%); health issues (27%); trial design (27%); lack of understanding (26%); and preferred current treatment plan (12%). Kay offered some potential solutions to increasing participation in brain tumour clinical trials, including: 1) introducing patients to clinical trials at diagnosis; 2) improving educational materials for providers and patients; 3) referring patients to navigators and advocacy organisations; 4) minimising financial barriers; and 5) rethinking trial designs and execution strategy.

Kay Verble

Marta Penas-Prado

Dr Marta Penas-Prado is a neurologist and neuro-oncologist originally from Spain but now working at the Neuro-Oncology Branch at the NIH as an associate research physician. She said that for every 100 patients with malignant glioma only 20% participate in clinical trials.

"Patients need to be aware that what is a standard treatment today was in clinical trials before," said Dr Penas-Prado. She said that slow enrolment numbers also means delays in getting new treatments from the lab into the clinic.

She added: "It's about patient education. We need to make a better effort in explaining the importance of clinical trials. As researchers, we also need to do a better job in getting new treatments to patients. There have been a lot of clinical trial failures. For example, one possible improvement in this area is the introduction of Phase 0 clinical trials, where the drug is administered prior to surgery, so we can determine whether it gets into the tumour or not."

Dr Penas-Prado also highlighted the plight of patients with rare brain and CNS tumours, such as ependymomas, oligodendrogliomas, medulloblastomas, or other embryonal tumours. She said that participation in clinical trials was close to zero percent in this patient population. "Why not include these patients in Phase I trials, which are only testing for safety?" she suggested.

Dr Penas-Prado also acknowledged the logistical difficulties some patients faced when enrolled in a clinical trial. "SNO/RANO have started an initiative to address barriers of enrolment into clinical trials," she said.

Dr Penas-Prado also addressed the issue of narrow eligibility criteria for clinical trials. She suggested that the answer lies in increased collaboration, including internationally, however this presents other difficulties such as having to deal with different regulatory agencies. "We have to do small trials which are hypothesis driven, and these involve a smaller number of patients." She gave the example of a trial to investigate whether a drug gets into the tumour, requiring around twenty patients. Following this, they can progress to confirmatory trials in multi-institutions.

Dr Marta Penas-Prado

Dr Ely Benaim

Dr Ely Benaim is a pediatric oncologist who, as Chief Medical Officer at Novocure in the United States, has extensive experience in conducting clinical trials. Dr Benaim explained that overall only 10% of cancer patients participate in clinical trials but in pediatrics it is 85-90%. "We don't give the children a choice," he said.

Dr Benaim said that there were very few private clinics for pediatrics but it was different in the adult world. "I feel for the people who are not in the major countries," he said, explaining that it was very difficult to add trial centres in the smaller countries. It could be that the company has no office in that country, or even if they get approval to conduct the trial, the therapy has no chance for registration or reimbursement there. "There are not many patients for some of these studies – there can be competition for patients [to enrol in clinical trials]," he added.

In suggesting some possible solutions for increasing participation in clinical trials, Dr Benaim proposed stepping up efforts to reinforce activities outside of academia, including raising awareness and education among clinicians. "Number one is patient education, but you also need to educate the doctors," he said.

In response to a question from the floor about clinical trials in sub-Saharan Africa, Dr Benaim pointed out that one issue is that the quality of the data is important and it requires the infrastructure to produce that quality. He said that the World Health Organisation (WHO) conducts some trials in Africa for large populations or diseases but that trials for rare diseases are much harder. "The Gates Foundation is also doing some work there," he added. Dr Benaim said that it might be different if there was a distinct patient population in a geographic location which suited a particular trial.

Dr Ely Benaim

Kathleen Wall

Kathleen Wall is a clinical research nurse at the Neuro-Oncology Branch at the NIH who manages patient participation in clinical trials. "There is still a negative connotation about clinical trials," Kathleen said. She added that there is mistrust among patients. She added that many patients saw clinical trials as being high risk. Sometimes the clinician will explain the trial but Kathleen will be required to explain it to them again in layman's terms. Like the other panellists, Kathleen stressed the importance of patient education.

There are also logistical barriers such as travel and accommodation to overcome. "Many trials are based in major centres, which means smaller centres or lower socio-economic areas are missing out," Kathleen said.

Kathleen Wall

Plenary Session 10

Moderator: Kathy Oliver, Chair, International Brain Tumour Alliance (UK)

Access to Therapies (compassionate use, off-label use, regulatory approval and HTA)

Panellists: Dr Mark Gilbert (Chief Neuro-Oncology Branch, CCR, NCI, NIH, US);

Linda Powers (CEO Northwest Biotherapeutics, US);

Irina Odnoletkova (VP Health Technology Assessment, Apogenix, Germany);

Suzanne Demko (Senior Clinical Analyst/Clinical Team Leader, US FDA);

David Jenkinson, Chief Scientific Officer (The Brain Tumour Charity, UK)

Panellists for plenary session 10 at the IBTA World Summit included (left to right): Linda Powers (CEO, Northwest Biotherapeutics), Irina Odnoletkova (VP Health Technology Assessment, Apogenix), David Jenkinson (Chief Scientific Officer, The Brain Tumour Charity), Suzanne Demko (Senior Clinical Analyst/Clinical Team Leader, US FDA), Mark Gilbert (Chief, Neuro-Oncology Branch, CCR, NCI, NIH)

IBTA Chair and Co-Director Kathy Oliver moderated plenary session 10

David Jenkinson

David Jenkinson, Chief Scientific Officer at The Brain Tumour Charity in the UK opened the discussion. David said he recognises the desperate need for patients to access new therapies, however as a scientist with over 20 years' experience in oncology research he had some words of caution.

"As patient advocates, we need to temper hope so that we are not promoting false hope. There are snake oil salesmen out there," he warned.

"We have to give good guidance and help people make decisions which are right for them, not give false hope and break them financially," he added. He also warned of the dangers of patients taking experimental medicines outside of clinical trials, saying this can cost money and time.

For nationalised health systems, reimbursement prior to approval could be looked at. For a pharmaceutical company to provide its product without reimbursement is a large financial undertaking. "A big company might be able to absorb those costs, but a lot of new therapies are being developed by smaller companies," he said. He believes NICE [the National Institute for Health and Care Excellence in the UK] needs to be quicker to support reimbursement after regulatory approval has been granted and that more compromises and reductions needed to be made in terms of drug pricing.

David Jenkinson of The Brain Tumour Charity, pictured above centre

Mark Gilbert

Dr Mark Gilbert said: "As a neuro-oncologist, sometimes I have patients to whom I can't offer the standard of care, or a clinical trial. How does one then navigate the idea of compassionate use?"

He added: "If we knew that a compassionate use drug would help people it would be a no brainer. However, the reality is far more complex. At what point do we feel comfortable recommending it to a patient? A certain level of safety? Why is this person not on a clinical trial? Is there a reason why they shouldn't be taking it?"

Dr Gilbert explained that sometimes a clinical trial has very tight inclusion criteria but the patient is able to access the drug on compassionate use. He emphasised that it is the mechanism of the trial which is important. He said: "It has to be done in a controlled setting. It is experimental in nature. The information needs to be captured. We will refer patients to a centre with carefully considered reasoning, or sometimes start a small trial of an FDA-approved drug." Dr Gilbert said that there is a role for compassionate use, so long as it is controlled and does not put the patient in the way of harm.

"We will not give a patient an experimental drug with no reasoning or control around it. We will not put the patient at harm," he emphasised.

Dr Gilbert said that he appreciates access programmes but the risks need to be appreciated and risks need to be mediated. Commenting on clinical trials, he added that many pivotal clinical trials arise out of excitement over earlier phase trials. Sometimes high response rates are seen in small trials, for example, everolimus in giant cell ependymoma. However, in GBM there have been impressive results in earlier phase studies but in phase III they fail. He said we need to be more clever in designing clinical trials and increase the use of collaborative science to help with go/no go decisions. "We need to ask ourselves," he said, 'is this really working? And if not, walk away. And if it doesn't work, we need to ask why it didn't work."

Dr Mark Gilbert, Neuro-Oncology Branch, NCI

Dr Gilbert was asked about repurposed drugs and said that, for example, metformin (a drug commonly used to treat Type 2 diabetes) had been tried in brain tumour clinical trials but it had not shown any effect. However, it might hold potential when used in conjunction with another drug.

Linda Powers

Linda Powers is the CEO of Northwest Biotherapeutics. She gave a very personal account from an industry perspective as well as someone whose family had been touched by cancer.

Linda has lost many family members to cancer, including her father to glioblastoma. As her father's advocate, she tried to help him get into a number of clinical trials and all of those efforts failed. She and her family experienced firsthand how difficult it can be for patients to enroll in clinical trials – especially older patients. They had also sought off-label access to temozolomide (not yet approved for brain cancer, then), initially failing but later obtained by travelling across the country. .

As CEO of Northwest Biotherapeutics, Linda has also been on the other side of the table working to bring a new therapy through to late stage clinical development, and finding that one of the key difficulties is achieving the necessary patient enrollment. Linda also touched on some of the other significant hurdles which Northwest has had to negotiate to this point, including financial and regulatory challenges.

Outside of their current trial for a dendritic cell immunotherapy, Northwest Biotherapeutics has treated over 170 glioblastoma patients, and additional non-glioblastoma patients, under compassionate use. Linda believes that patients need more say in decision making, and more access to new treatments through compassionate use. Linda explained that Northwest Biotherapeutics collects all the data from their compassionate use patients. Patient groups can help enormously by increasing contributions of compassionate use data to data registries.

Linda Powers, Northwest Biotherapeutics

Suzanne Demko

Suzanne Demko is the Clinical Team Leader of the Neuro-Oncology, Pediatric Oncology and Rare Tumors Group at the United States Food and Drug Administration (FDA). Speaking firstly to off-label drug use, she sees the biggest problem as payment. In the United States, many insurance companies will not pay for drugs used off-label. She added that the FDA has nothing to do with payment or reimbursement of drugs.

Turning to Expanded Access (compassionate use), Suzanne explained that this was a type of intermediate access where patients with a serious or life-threatening disease gain access to an investigational product (which is yet to be FDA approved) outside of clinical trials. She said that treatment access protocols for compassionate use are designed by the pharmaceutical companies, but the FDA can grant Expanded Access on an individual patient basis if requested through a physician.

A recent initiative to streamline this process is Project Facilitate which offers physicians a single point of contact at the FDA to simplify the application process. Suzanne said that the FDA receives over 50 patient requests per month, either through a physician or direct from the family, and 97% of these are approved. "We support the patients' right to choose," she said.

The FDA is open to new trial designs, Suzanne Demko said, including trials which test drug combinations. She said a first step is to assess the safety of the drug combination.

Suzanne Demko, FDA, pictured above (centre)

Irina Odnoletkova

Dr Irina Odnoletkova is VP Health Technology Assessment at Apogenix, a private company which is developing an immunotherapy treatment currently undergoing clinical trials in recurrent glioblastoma. Prior to her position at Apogenix she was employed by a Belgian healthcare payer organisation.

Dr Odnoletkova said that most European countries now operate nationalised health systems and many European countries are now employing HTA tools which may look at a range of issues such as: 1) overall burden of the disease, 2) availability of treatment alternatives, 3) clinical comparative effectiveness, and 4) cost effectiveness. Each system looks at how to assess the relevant benefit to the patient.

Some countries don't address the cost effectiveness of a treatment, while others allocate a price tag.

In the case of compassionate use, Dr Odnoletkova said that we need to consider carefully what the options are for patients. "There is a role for patient organisations to challenge the authorities," she said.

Irina Odnoletkova, Apogenix, pictured above (centre)

SUMMARY

THE Summit concluded with closing remarks from Dr Mark Gilbert and Kathy Oliver.

Dr Gilbert conveyed his sincere gratitude to delegates for travelling from around the world to NIH for the Summit. The engagement with patient advocates was a unique opportunity to hear first-hand about the impact brain tumours had on people's lives.

In thanking the staff and clinicians at NIH, and as a symbol of collaboration, Kathy Oliver presented Dr Gilbert and Dr Terri Armstrong with an inflatable globe marked with the countries represented at the Summit. Kathy also thanked all the Summit presenters for their powerful and moving stories which she said sent a clear message that we need to do better, that we have to give hope, and that we need to continue to collaborate and build bridges.

Participants expressed how much they enjoyed the Summit and how much they had learned from it. Being at a world class research and treatment facility such as NIH was clearly a highlight for many people. The opportunity to hear from, and engage with, a number of leading specialists in brain tumour treatment and research was an invaluable experience.

Also notable was the spirit and camaraderie generated among Summit participants, ensuring a positive atmosphere of hope and support throughout the meeting. Everyone is now looking forward to the next IBTA Summit in 2021! ■

2019 World Summit of Brain Tumour Patient Advocates Participants

Hugh Adams

Brain Tumour Research
Funding the fight

Jean Arzbaecher

THE UNIVERSITY OF ILLINOIS COLLEGE OF MEDICINE
CHICAGO PEORIA ROCKFORD URBANA
UIC

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Kenneth Aldape

NIH NATIONAL CANCER INSTITUTE

Irene Azong-Wara

JACOBS HOPE FOUNDATION

Terri Armstrong

NIH NATIONAL CANCER INSTITUTE

Jenny Baker

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Anna Arnaut

GLIA
CROATIAN BRAIN TUMOR ASSOCIATION

Amanda Bates

National Brain Tumor Society

David Arons

National Brain Tumor Society

Mandy Bathan

He waka eke noa
brain tumour support NZ
In it together

Ely Benaim

Brittany Cordeiro

Neil Bindemann

Maureen Daniels

Helen Bulbeck

Lena Davidsson

Yaron Butterfield

Co-chair of the BC Cancer Patient and Family Advisory Council (PFAC)

Melanie Davies

Andreia Capela Marques

Medical oncologist, Portugal

Liz Dawes

Rosemary Cashman

John de Bruin

Ralph DeVitto

American Brain Tumor Association®

Richard Gillette

Jelle de Vries

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Anita Granero

Oscar's Angels
Oscar's Angels Rota
IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Nitin Garg

BTSG Awareness Foundation

Brock Greene

OLIGO NATION
UNITING FOR A CURE

Laureline Gatellier

NPO 法人 脳腫瘍ネットワーク
JAPAN BRAIN TUMOR ALLIANCE

Barbara Haake

novocure™
patientforward

Mark Gilbert

NIH NATIONAL CANCER INSTITUTE

Tracey Hanover

novocure™
patientforward

Kristen Gillette

Chas Haynes

SNO Society for NeuroOncology

Catherine Hindson

BRAIN TUMOUR ALLIANCE AUSTRALIA

Fiona Keegan

BRAIN TUMOUR IRELAND

Ron Hirsch

students SUPPORTING brain tumor RESEARCH

Paul Kluetz

US Food and Drug Administration (FDA)

Petra Hoogendoorn

goings-on

Carol Kruchko

CBTRUS — Central Brain Tumor Registry of the United States

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

David Jenkinson

THE BRAIN TUMOUR CHARITY

Sharon Lamb

IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Delores Kannas

endbraincancer

Ilyse Lax

THE GERRY & NANCY FENCER BRAIN TUMOR CENTRE

Brett Kavaja

Celgene

Rolf J. Ledal

Hjernesvulstforeninger

Heather Leeper

NIH NATIONAL CANCER INSTITUTE

Robin Meltzer

Brain Tumour Research
Funding the fight

Lia Le Roy

Duane Mitchell

Co-Director, Preston A Wells Jr Center for Brain Tumor Therapy
Director, University of Florida Brain Tumor Immunotherapy Programme

Melissa Lim

BRAIN TUMOUR SOCIETY (SINGAPORE)

Tina Mitchell Skinner

BRAIN TUMOUR SUPPORT
Together WE are Stronger

Magdalena Magiera

GLIOMA FOUNDATION CENTER

Jessica Morris

OurBrainBank
Moving Glioblastoma from terminal to treatable.
Powered by patients.

Mary Ellen Maher

Northwestern Medicine
IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Yuko Moue

小児脳腫瘍連絡会
PBTN Pediatric Brain Tumor Network
RCJ

Susan Marshall

braintumour foundation OF CANADA

Christine Mungoshi

ZIMBABWE BRAIN TUMOUR ASSOCIATION
IBTA INTERNATIONAL BRAIN TUMOUR ALLIANCE

Kristie Naines

BRAIN TUMOR NETWORK™
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Marta Penas-Prado

NIH NATIONAL CANCER INSTITUTE

Edjah Nduom

NIH National Institute of Neurological Disorders and Stroke

Ciara Peters

BRAIN TUMOUR IRELAND

Irina Odnoletkova

apogenix

Bec Picone

peace of mind
Brain Cancer Support here and now

Gordon Oliver

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Linda Powers

NORTHWEST BIOTHERAPEUTICS

Kathy Oliver

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Erik Ramos

NORTHWEST BIOTHERAPEUTICS

Michelle Patterson

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Sarah Rigby

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Christine Siegel

Simone Silenzi

Lisa Simms Booth

Formerly with the Biden Cancer Initiative

Jaye Bea Smalley

Zrinka Susnjara

Brett Theeler

Chris Tse

International Brain Tumour Alliance

Christina Tsien

Washington School of Medicine

Kay Verble

The Sontag Foundation

Suzanne Wait

All.Can Changing cancer care together

The Health Policy Partnership (research, people, action)

Kathleen Wall

NIH National Cancer Institute

Kim Wallgren

cernfoundation Collaborative Ependymoma Research Network

Nicole Willmarth

American Brain Tumor Association®

Jing Wu

NIH National Cancer Institute

Katarzyna Zarychta

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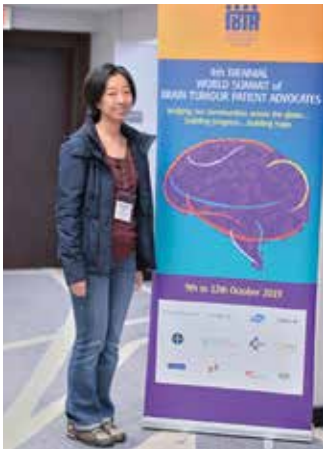
From the 2019 IBTA World Summit Album



The Lithuanian Brain Tumour Patients and their Caregivers Society: celebrating our fifteenth anniversary

Aistė Pranckevičienė, PhD
Lithuanian University of Health Sciences, Neuroscience Institute, Kaunas, Lithuania
Laura Šalčiūnaitė, Psy.M
Lithuanian University of Health Sciences, Neuroscience Institute, Kaunas, Lithuania

The Lithuanian Brain Tumour Patients and their Caregivers Society (LBTPCS) celebrated its fifteenth anniversary in June 2019. These fifteen years were not an easy journey. The Society went through periods of enthusiasm and activity, as well as some periods of slowdown. However, we are happy to share our story and lessons learned.

The Beginning

The LBTPCS was established in 2004. Its first and longstanding president, Brone Vengeliauskiene, when remembering the birth of the organization says: "My daughter got sick with brain cancer in 2001. At that time the treatment situation in Lithuania was miserable. Modern neurosurgical and neuroimaging equipment was not available, and the main chemotherapy option for malignant gliomas – temozolomide – was very expensive and the treatment was not covered by our national health insurance system. Neurosurgeons and neuro-oncologists were actively trying to change this situation. They were writing letters to the Ministry of Health requesting to include temozolomide in the list of drugs covered by health insurance, but things did not change. Thus, neurosurgeon Professor Vytenis Deltuva, who treated my daughter at the Hospital of the Lithuanian University of Health Sciences in Kaunas, approached me, encouraged me to take leadership, and to establish a patients' organization. "Politicians may not listen to doctors," he said, "but maybe they will be more sensitive to the voices and advocacy of patients."

That's how idea of the LBTPCS was born.

(Left to right) Psychologists Laura Salciunaite, Aiste Pranckeviciene and Diana Gabrijolaviciute who all work with the Lithuanian Brain Tumour Patients and their Caregivers Society

High tide

The first standing committee of the LBTPCS mainly included caregivers and doctors and they all took active steps by talking and spreading information about brain tumour patients' needs.

Brone Vengeliauskiene said: "We even went on a TV show to talk about our needs. When you don't have an illness, it is hard to understand why millions should be invested into expensive medical equipment or drugs. We must educate society about how devastating it is to have a brain tumour". ➤

Former President of the Lithuanian Brain Tumour Patients and their Caregivers Society Brone Vengeliauskiene whose daughter was diagnosed with a brain tumour in 2001

Current President of the Lithuanian Brain Tumour Patients and their Caregivers Society Lina Piliciauskiene (left) and Vice-President Professor Vytenis Deltuva (right)

However, it is hard to be heard when you are representing such a rare disease as a brain tumour. That is why collaboration with the Lithuanian Cancer Patient Coalition (POLA) was started. POLA is a non-governmental umbrella organization uniting many oncology-related organizations, including cancer patients' societies, and offering personal, legal and political support for people with cancer.

Brone Vengeliauskiene remembers: "We also started raising funds and we were very successful in collecting donations. We established some scholarships and supported training of some doctors. I strongly believe that we should invest not only in patients, but also in science and education. We also helped the hospital to obtain some equipment that made hospital stays more comfortable. But of course, our main achievement was inclusion of temozolomide in the list of drugs that are covered by our national health insurance."

Our mission

The mission of LBTPCS then and now is to unite those who are affected by a brain tumour and those interested in this disease, including patients, their families, healthcare professionals and researchers. The vision of our growing community is to represent the voice of patients and to increase healthcare opportunities and overall quality of life, by providing information, education and support.

To this day, the main goals of our Society remain:

- To educate patients and their families about brain tumours, their impact on people's everyday lives and how to cope with this disease, by spreading accurate information in hospitals, booklets, online, as well as organising educational training
- To be the advocates of brain tumour patients while communicating with public institutions and health care providers, aiming to increase availability of the newest treatment options for neuro-oncological disorders and to ensure comprehensive care for patients and their caregivers
- To ensure non-medical support, which includes psychological and social help, provided not only by professionals but the community members themselves – this includes live support group meetings and online groups, in order to help patients stay connected
- To help doctors raise their qualifications and introduce new services; support and encourage scientific research and implementation of scientific results in clinical practice
- To collaborate with other Lithuanian and international organizations, learning from their good experiences of organizing support for brain tumour patients
- Finally, to raise awareness of neuro-oncological diseases by spreading information about the newest scientific studies into prevention as well as opportunities for modern treatments.

Slowdown

It is a challenge to keep organizations active and productive when its members are patients who are very sick. Brone Vengeliauskiene's daughter lost her fight with cancer after eleven years but Brone continued her work at LBTPCS.

Brone said: "Continuity and leadership are always a challenge in such organizations. People are very motivated to participate in an organization when they are in active treatment, but they disappear when the illness is stable or controlled, or they become too sick to continue. Most caregivers step aside when they lose a loved one. And you cannot rely only on doctors because they have other duties.

The Lithuanian Brain Tumour Patients and their Caregivers Society meets monthly at the Hospital of the Lithuanian University of Health Sciences

You must work very proactively to include new members to keep going. It is a hard job."

Fresh start

From the establishment of LBTPCS, its main objective was active advocacy to ensure the best possible treatments. Less attention was paid to the psychological needs of patients and caregivers.

But in 2019 a team of psychologists – Aiste Pranckeviciene, Diana Gabrijolaviciute and Laura Salciunaite – with the warm and encouraging support of the new LBTPCS president Lina Piliciauskiene and the administration of the Neurosurgery Department at the Hospital of the Lithuanian University of Health Sciences (LUHS) initiated support groups for brain tumour patients and their caregivers.

Dr. Aiste Pranckeviciene is a medical psychologist working in the Neurosurgery Department. Diana Gabrijolaviciute is a PhD student who came to the Neurosurgery Department for her professional practice training during her Master's studies. Diana was so taken up by brain tumour patient needs that she devoted her Master's thesis to the psychological experience of being ill with a brain tumour and she plans to continue this topic in her PhD research

Laura Salciunaite is a Master's student whose enthusiasm during professional practice training in the Neurosurgery Department was the final ingredient to let the brain tumour patient and caregiver support groups happen.

The first support group took place in October 2019 celebrating the International Brain Tumour Awareness Week. Support groups are organized once a month at the Neurosurgery Department of the Hospital of LUHS. We are very happy seeing the growth of community and increasing patients' participation. Yet, there is still a lot to be done, which makes us believe that our journey as a community and family has only just begun. ■

IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE

The IBTA maintains a list of neuro-oncology and relevant cancer conferences on its website at

www.theibta.org

Stereotactic radiosurgery for brain tumours

Mr H Ian Sabin, BMSc FRCS(Ed) FRCS(Eng)
Consultant Neurosurgeon and Medical Director, London Gamma Knife Unit,
Wellington Platinum Medical Centre, London, UK

Brain tumours of all types have been treated by surgery since the late 1800s, radiotherapy since the orthovoltage era in the 1940s and much more recently, chemotherapy, often guided by tumour genetics.

In a relatively short article, it is not possible to go into detail about each of the many different brain tumours but in general terms it is possible to categorize them as non-cancerous or 'malignant' (cancerous). Although all brain tumours are uncommon, among the non-cancerous group the types most frequently encountered include vestibular schwannomas (acoustic neuromas), meningiomas and pituitary tumours. Of the cancerous tumours, examples include gliomas (astrocytoma, oligodendroglioma, glioblastoma) and secondary deposits from cancers elsewhere in the body known as "brain metastases" (the commonest cause of 'brain tumours').

A brief introduction to stereotactic radiosurgery

Traditionally, non-cancerous tumours were treated surgically, and brain metastases treated with whole brain radiotherapy, generally delivered in daily fractions over two to three weeks. There has been a significant change in practice over the past 30 years, driven by the development of better forms of radiotherapy delivery, in particular stereotactic radiosurgery.

Stereotaxy refers to the accurate localisation of targets in 3D space and radiosurgery is used to describe delivery of radiation in up to five daily fractions, although many treatments are single fraction and delivered in one day. There are various machines now available to deliver this type of radiation, which is often described as 'focussed', although it is not possible to focus radiation and instead we converge multiple beams on the target, each beam being


Ian Sabin, consultant neurosurgeon in London

delivered from a different entry around the head thus maximising the dose to the target and limiting the dose to the brain around.

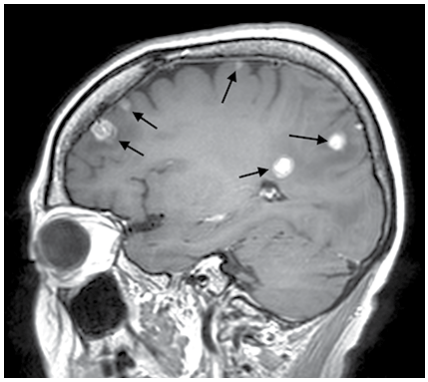
The radiosurgery machines in common use today include the Gamma Knife, CyberKnife and adapted Linac radiotherapy machines such as TrueBeam. In addition, proton treatments are available in Europe, Japan and the USA, with centres now opening in the UK, and these may confer some advantage for a relatively small number of patients, although protons have not been proven to be better for the vast majority of tumours currently treated with standard radiosurgery. Are any of the above machines better than the others for the treatment of brain tumours? This has not been shown in clinical practice, although there are differences in the way each machine delivers dose, the ability of the planning software to deal with multiple targets on the day of treatment, the fixation method used to keep the head still during treatment and the time needed to complete the treatment.

Many people think that radiotherapy is used only for cancer treatments and are surprised when it is offered to treat non-cancerous tumours in and around the brain. The development of better systems to pin-point and deliver high dose radiation to a target in the head has been pivotal in the revolution which has occurred in neurosurgical treatment for many patients.

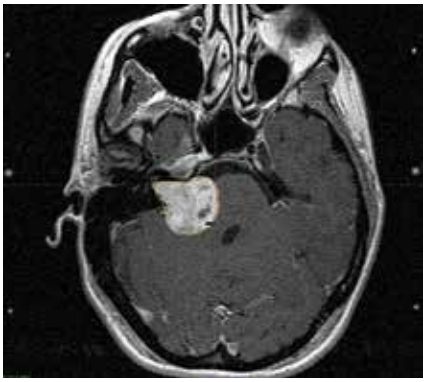
Standard, 'external beam radiotherapy', is delivered in daily small doses up to a total dose which varies according to the condition being treated, but may involve anything from two to six weeks of treatment. This regimen developed because of the wide fields being irradiated with a significant risk of injury to the tissues surrounding a tumour. By only giving a small dose each day, the tumour is damaged preferentially due to its relatively rapid growth rate and increased sensitivity to radiation, while the normal surrounding tissue has time to repair itself between doses. Even when given in this way, there is a maximum tolerance of the surrounding normal tissue which will limit the total dose delivered.

This fractionated approach has stood the test of time for malignant disease, although even here new technology has improved the delivery of radiation and reduced the risk of adverse radiation events (ARE) – essentially damage to normal organs and tissue adjacent to or surrounding the tumour being treated. For non-cancerous tumours, however, the sensitivity of the lesion being treated is not much greater than the tissue around it. This makes fractionation less likely to be effective as the dose needed to kill the tumour is very similar to the tolerance of its surroundings. Some tissues are much more sensitive than others, for example hair loss after radiotherapy to brain tumours is commonly seen, and the tolerance of the optic nerves has to be respected if loss of vision is to be avoided.

I generally inform my patients that we



Brain scan showing five cerebral metastases. It is now common to treat 15-20 metastatic deposits in a single session of radiosurgery, assuming that the individual has a good quality of life and their systemic disease is controlled.



Radiosurgery treatment plan for a vestibular schwannoma. The red line defines the tumour, with the chosen marginal dose of radiation shown in yellow. In general, the closer the yellow is to the red, the better the plan.

are able to kill anything with radiation, but the trick is not to make the cure worse than the disease by causing catastrophic injury to normal structures. Stereotactic radiosurgery allows us to give a high dose of radiation to the target, with a low dose to the surrounding brain and the 'organs at risk' such as the optic nerves, pituitary gland and brainstem.

Uses for stereotactic radiosurgery

So, what can we treat successfully with radiosurgery? To be effective we need to be able to see a well-defined target on planning scans and to be able to deliver an effective dose to it accurately, with minimal spill into normal brain. In practice the conditions we treat most frequently include:

- **non-cancerous tumours: vestibular schwannoma, pituitary, meningioma**
- **Malignant tumours: cerebral metastases**
- **Trigeminal neuralgia**
- **Vascular malformations**

Not included in the list are the primary malignant brain tumours – gliomas. Standard therapy for these remains surgical debulking where possible, usually followed by standard external beam radiotherapy and chemotherapy for the aggressive gliomas. Radiosurgery is occasionally offered to patients if a small area of recurrence is found on follow up scanning.

Without a doubt, the commonest indication for radiosurgery currently is for cerebral metastases, which in the USA account for 60-70% of a unit's case load. In the UK we have been slower to adopt radiosurgery rather than whole brain radiotherapy (WBRT), but this is now changing, mainly due to the emergence of novel systemic treatment agents which can selectively target cancers. These agents are increasingly successful for tumour metastases in organs such as the liver and lungs, but struggle to penetrate into brain tissue due to the so called 'blood brain barrier' which prevents drugs entering the brain due to 'impermeable' blood vessels. Here a dual attack is common, with radiosurgery being used to target the metastatic brain tumours and systemic therapy to tackle the original cancer elsewhere in the body.

WBRT is still a useful tool. However it has become clear that there are problems with memory and concentration after generalised brain irradiation and these effects become more obvious as patients live longer due to the better systemic treatments. These issues are avoided with stereotactic radiosurgery as the dose to the brain as a whole is very much less, with less 'collateral' damage as a result.

Outcomes following radiosurgery are generally excellent, with 'control' rates being in the 90% range for most of the tumour types we treat. Complications can occur, but the risks of these occurring are dependent almost entirely on the dose of radiation given, the size of the lesion being treated and the location of the tumour within the brain. These risks should be fully explained by the involved clinician during pre-treatment consultations to allow the patient to make an informed choice, guided by their doctor.

In summary, for patients with appropriate brain tumours, precise, targeted radiosurgery offers a very effective treatment, with low risks and a high chance of successfully stopping tumour growth. It is usually one of a number of options and patients will need some guidance from their doctor regarding the best form of treatment for them as individuals. ■

What's news?

To receive your free copy of *Brain Tumour* magazine, please visit: https://theibta.org/our-publications/#e-News

The IBTA also publishes a monthly e-News containing information of interest to our international brain tumour community such as treatment advances, cutting edge research, patient organisation news, industry news relevant to brain tumours and a listing of forthcoming conferences and meetings. Please visit: https://theibta.org/our-publications/#e-News to subscribe.

Spaeth Family Walk to honour three loved ones and raise awareness of brain tumors

The Spaeth/Olson family in the United States has a triple reason to raise awareness of brain tumors. Three siblings in the Spaeth family were diagnosed with a brain tumor: Gilbert Spaeth, Elizabeth (Betty Spaeth) Breitbach and LeRoy Spaeth.

As three of eight children (three boys and five girls), Gilbert, Elizabeth and LeRoy were raised on a dairy and crops farm in central Minnesota, USA, in the mid 1900s. Elizabeth was diagnosed with an astrocytoma in February 1988; Gilbert was diagnosed with a glioblastoma in July 2001 and Le Roy was also diagnosed with a glioblastoma in April 2008.

Jill (Spaeth) Olson is Gilbert Spaeth's daughter and she told *Brain Tumour* magazine: "It's over 17 years since my father's death from a brain tumour. My heartfelt wish and desire is that someday we will have a cure for all brain tumors. In honor of my dad, I pray that that I will see a cure in my lifetime, thus giving many people the chance to survive this cancer.

"Our family members all very much enjoyed doing an International Brain Tumour Awareness Week Walk over the weekend of 26th and 27th October, 2019 as is evident in our photographs from family groups in Atlanta [Georgia], Hastings [Minnesota] and Washington DC. We plan on doing this every year going forward." ■

ZBTA walks in Harare for brain tumours

Christine Mungoshi, the Director of the Zimbabwe Brain Tumour Association (ZBTA) wrote to tell us: "On the 2nd of November 2019, the ZBTA team was joined by seventeen volunteers and supporters from the communities around the Harare suburbs of Waterfalls, Warren Park and Kuwadzana to commemorate the International Brain Tumour Awareness Week, by walking from the Harare Post Office to The Kopje, a distance of 2.8 kilometres.

"The photos here show our ZBTA volunteers and supporters who were full of enthusiasm when they walked up to the summit of The Kopje.

"The Kopje is one of the highest places in Harare. Here, you can have a bird's eye view of the city. Historically (pre-colonial era) it was the residence of the popular Chief Neharawa, after which Harare is named. Chief Neharawa is reportedly buried within the vicinity of The Kopje. The name Harare means, "he does not sleep". The actual Kopje area covers around 15 hectares (37 acres) and was declared a National Heritage site in 1968." ■

Brain Tumour Research Walks of Hope

UK-based charity Brain Tumour Research hosts a series of events every September called Walks of Hope.

Initially starting as an annual Canal Walk in the charity's home county of Buckinghamshire, the event expanded over the years. In 2019, some 500 supporters across the UK took to the great outdoors to join various regional Walks of Hope. An incredible 2,110 miles was covered and tens of thousands of pounds raised for Brain Tumour Research.

In 2020, the Walks of Hope went virtual to adapt to ongoing coronavirus restrictions. The response was overwhelming with more than a thousand people across the UK (and some from across the world) registering to take part.

Charity supporter Lauren Neville was diagnosed with a glioblastoma multiforme (GBM) brain tumour in 2018. Despite initially being told she had six weeks to live, Lauren defied the odds and in September walked eight miles with her partner and two children. As well as raising awareness, the family raised more than £1,400 – an amazing achievement.

The family of two-year-old Sidney Eyre completed a Walk of Hope around their hometown in West Yorkshire. Sidney was diagnosed with a brain tumour in February 2020, but thankfully remains fit and well. He joined his mother, aunty and cousins to raise £600.

Just 15 months after being diagnosed with a GBM, Sue Davies passed away in August aged 55. Six months after Sue's diagnosis, her family received a further blow as her husband Mark was told he had blood cancer. Walking around the Jinney Ring in Bromsgrove, the family raised more than £900 in Sue's memory.

More than £160,000 was raised from the Walks of Hope in 2020. These funds will help the charity in its mission to build a network of experts in sustainable research at dedicated UK Centres of Excellence whilst influencing UK governments and larger cancer charities to invest more nationally in brain tumour research. ■

IX International Brain Tumour Awareness Day Symposium in Bucaramanga, Colombia

Gabriel Vargas MD

Honorary President of the Oncologic Neurosurgery section of the Latin American Federation of Neurological Societies (FLANC) and lead coordinator of the event

For the ninth consecutive year the city of Bucaramanga carried out three different activities in honor to the International Brain Tumour Awareness Week.

We participated and completed the XVI City of Bucaramanga Marathon 2019 in honor of brain tumor patients. We held a pre-symposium, special, interactive course about brain tumour surgery with an emphasis on awake craniotomy patients taught by our special guest from France, Dr. Hughes Duffau. Finally, we had the main event with more than 230 participants - The IX International Brain Tumour Awareness Day Symposium which took place at The Universidad de Santander (UDES) where many subjects about advances in brain tumour surgery were discussed by local and international specialists in these topics. The sessions were directed to health care professionals and students and patients and families who, at the end of the symposium had the opportunity to express their thoughts and experiences of the whole process for their brain tumor treatments.

These events were sponsored by the Society of Neurooncology Latin America (SNOLA), the Section of Oncologic Neurosurgery of the Latin American Federation of Neurosurgical Societies (FLANC), the Section of Oncologic Neurosurgery and Skull Base Surgery of the Colombian Neurosurgery Association, the University Hospital Los Comuneros, Chicamocha Clinic, and very special support from The UDES, which, at the Symposium had the honor of rendering the Honoris Causa title to Dr. Hughes Duffau for his advances and contributions to neurooncology around the world. ■

Health care professionals, students, brain tumour patients and families who participated in the Symposium

Neurosurgery research group of students from The UDES, patients and families who participated in the XVI City Of Bucaramanga Marathon 2019, in honor of brain tumor patients and promoting The International Brain Tumour Awareness Week

Left: The pre-symposium, special, interactive course about brain tumour surgery with emphasis on awake craniotomy patients taught by our special guest from France, Dr. Hughes Duffau

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Brain Tumors Research Association

To support
neuro-oncological research

The Association's main goals are to improve basic, translational, and clinical research in the field of brain tumors and to support hospital services.

To act specifically

The ARTC deals mainly with primary brain tumors. Research laboratories and clinical Departments are supported directly and through fellowship grants. A particular attention is paid to research on quality of life issues. Moreover, ARTC recently developed a program to support neurooncology training and care in French-speaking Western Africa.

a.r.t.c@free.fr

Association pour la Recherche sur les Tumeurs Cérébrales
Groupe Hospitalier Pitié Salpêtrière
Fédération de Neurologie – Mazarin
47, Boulevard de l'Hôpital 75013 PARIS

www.artc.asso.fr

National Brain Tumor Society

Conquering and curing brain tumors — once and for all

We are pleased to stand beside our friends at IBTA in the fight against brain tumors.

WWW.BRAINTUMOR.ORG

@NBTStweets @braintumors
@natlbraintumorsociety

BRAIN TUMOUR REGISTRY OF CANADA
EST. 2019

Making every brain tumour count

Brain tumours are unpredictable and complex. They can affect vision, hearing, memory, balance, and mobility. Their effects are physical, emotional, financial, and last a lifetime.

There is no cure.

Until recently, Canada has relied on data from a number of American and Canadian data resources to guide Canadian research, raise awareness, secure government funding and provide support programs.

In 2019, that changed with the launch of the first all-Canadian Incidence Report on malignant and non-malignant brain tumours. In 2020, that was followed by a Survival Report, again using all-Canadian data collected from four provinces representing 70 per cent of the population.

Go to **www.braintumourregistry.ca** to learn more.

Rare Cancers JAPAN

rarecancersjapan.org/en/
contact: info@rarecancersjapan.org

OUR OBJECTIVES -In the era of genomic medicine-

Improve medical care system for rare cancer patients.

Develop better treatments (surgery, drug therapy, radiation therapy, immunotherapy, nuclear medicine, etc.)

Accelerate basic research, translational research, and clinical trials to find a cure.

Create a society more adapted to rare cancer patients and their caregivers and provide them with relevant information and a higher quality of life.

OUR NETWORK IN JAPAN

Cure Sarcoma
DIPG Symposium Organizing Committee
Ewing Sarcoma Patient Family Group
Family support group for Retinoblastoma (Sukusuku)
GISTERS
Japan Association Mesothelioma and Asbestos Related Disease Victims and their Families
Japan Brain Tumor Alliance (JBTA)
Japan Sarcoma Patients Network "TANPOPO"
Lisianthus support group for Children Diseases
Melanoma Patients Association - Over The Rainbow
Neuro-Endocrine Tumor Patients Association (PanCAN Japan)
Pediatric Brain Tumor Network of Japan (PBTN)
PMP patients' Network of Japan
Rare Cancer Patients' Network
Rhabdomyosarcoma Family Network
Thymoma and Thymus Cancer Patients' Association "Futatsuba"

COVID-19 doesn't stop the annual Kortney's Challenge Fun Run/Walk

Kristen Gillette, Founder/Executive Director of the Kortney Rose Foundation

United States

KORTNEY ROSE FOUNDATION

The Kortney Rose Foundation (KRF), based in New Jersey, USA, held its 15th annual Kortney's Challenge 2 Mile Fun Run/Walk virtually, due to COVID-19. Just over 500 people, including 36 teams, participated, representing 36 U.S. states, as well as Australia, Poland, England, Curacao and Switzerland. The race raised $64,000 to support collaborative research efforts to find better treatments and cures for pediatric brain tumors.

This year Kortney's Challenge was a weekend event, kicking off on Friday, July 31st with a livestream opening ceremony that included the US national anthem sung by brain tumor survivor, Brett Roysdon; a virtual start by Ryan (a brain tumor warrior) and his sister, Ella; and a group of runners led by the Blue Nights New Jersey XV International Law Enforcement Motorcycle Club. People walked and ran over the weekend and posted photos from around the world. The weekend closed with a video thank you by Ludrianna Bazile, another brain tumor survivor. Team Run #BFE (Best Family Ever), with 72 members, was the largest team and raised the most in donations - over US $16,000.

The Kortney Rose Foundation is a 501(c)(3) charity created by nine-year-old Kortney Rose Gillette's parents after her death in 2006 from a rare brain tumor. The charity was established to create Kortney's legacy of helping other children with brain tumors through the promise of research. Since inception the Foundation has built a playground in Kortney's name, is responsible for over US $2 million in funding for pediatric brain tumor research and helped to establish the world-class Children's Brain Tumor Network (CBTN) - formerly the Children's Brain Tumor Tissue Consortium (CBTTC).

Kristen Gillette, Founder/Executive Director of the Kortney Rose Foundation said: "We understand it's a difficult time for everyone right now, and we're truly grateful to those who continue to make it a priority to share their time, effort and resources. No matter what else is happening in the world, kids continue to get diagnosed with, treated for, and die from brain tumors. We can't take our foot off the gas now that we've finally started to see forward momentum over the past ten years. The Kortney Rose Foundation will continue with the pedal to the metal." ■

Team Ludri (Left to right)- Ludrianna Bazile, brain tumor surviving warrior, her mom Kathy and dad, Ludwisch

Right: Kortney's friends (left to right: Kaelyn, Miranda, Jess and Ethan) got together and ran as a team called 15 Years Running.

Dr. Cassie Kline, Inaugural Kortney Rose Foundation Clinical Researcher in Neuro-Oncology at Children's Hospital of Philadelphia (CHOP) and son

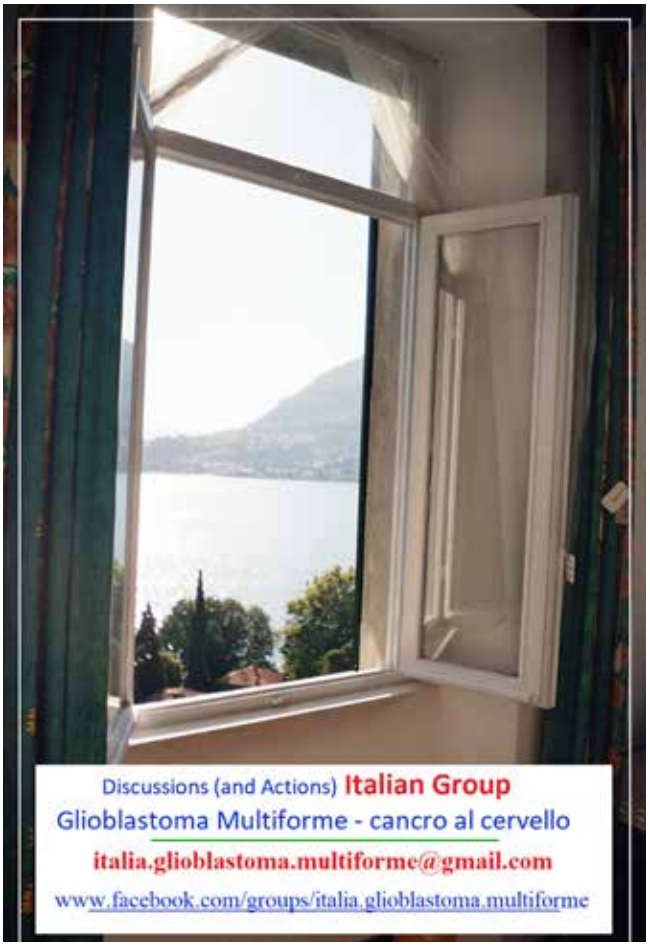
The Tindall Family participating in Team RUN #BFE which had 72 participants and raised over $16,000 for brain tumor research in honor of brain tumor warrior Ryan

An enthusiastic group (from Savannah, Georgia, US) of the Delta Xi Chapter of Sigma Beta Xi Sorority Inc also participated virtually in the 15th annual Kortney's Challenge

Jason Cain and family from Melbourne, Australia. Jason (right) is a pediatric brain tumour researcher at the Hudson Institute in Australia

12th Annual Nick Gonzales Charity Golf Tournament and Fundraising Dinner

CINDY Villarreal of the Nick Gonzales Foundation in the United States wrote to us to say: "In 2019, our golfers walked an 18-hole course to support brain tumor patients around the world, totalling over 440 combined miles for the Walk Around the World for Brain Tumours. The event was sold out with 118 golfers and over 250 guests. It netted over $50,000 from golf registrations, silent and live auctions, corporate sponsorships and In Memorial donations. The 12th Annual Charity Golf Tournament was held at The Tribute Golf Course in The Colony, Texas. This golf course was designed by Tripp Davis, a renowned golf course architect, in tribute to some of the most famous golf courses in Scotland. We even had a special bagpiper starting the event!" ■



Celebrating 20 years creating a CIRCLE of HOPE

RAISING FUNDS AND AWARENESS FOR PAEDIATRIC BRAIN TUMOUR RESEARCH

MEAGAN'S HUG

OUR VISION IS TO CREATE A WORLD WHERE NO CHILDREN AND THEIR FAMILIES SUFFER FROM BRAIN TUMOURS

meaganshug.com

registered charity number:

77407 7473 RR0001

Formerly operating as Meagan's Walk

PVW Brain Tumor Foundation

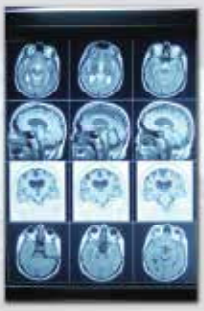
We …

- raise awareness of brain tumors in the community, and
- provide support to those affected by brain tumors

Set up in Hong Kong in honor of bass trombonist Pieter Vance Wyckoff, we encourage everyone to *Play Your Part*!

www.pvwbraintumorfoundation.org.hk

MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION INC



Hewlett, NY Virtualtrials.com

Patient Education and Support
- NEW! Copayment Assistance Program!
- NEW! Drug Discount Card Program!
- Clinical Trials & Noteworthy Treatments For Brain Tumors website at virtualtrials.com
- Brain Tumor Guide for the Newly Diagnosed
- Brain Tumor News Blast
- Online Support groups
- Extensive video library
- Brain Tumor Virtual Trial
- Toll Free Patient Help Line: 1-888-295-4740

Brain Tumor Research
- Funded over 40 brain tumor research projects
- Fundraising for brain tumor research

Brain Tumor Activism
- Organizes the brain tumor community to fight for FDA approval of drugs and devices, as well as insurance company payments for these treatments.

We need your help!

We have many research projects that are just waiting to be funded!
We need your help to run fundraisers for us.
100% of the money you raise for us will go to a research project!
No experience needed - we will help you!

Member of the Grey Ribbon Crusade http://GreyRibbonCrusade.org

Brain Tumour Awareness Day in Argentina

Alejandra T Rabadán, MD, PhD, IFAANS

Chief of Division of Neurosurgery. Institute of Medical Research A Lanari. University of Buenos Aires, Argentina

The 9th Brain Tumor Awareness Day in Argentina was organized as a joint meeting with the Section on Tumors and Skull Base of the Argentine Association of Neurosurgery (AANC).

It was held in Mendoza City from 31 October to 1 November 2019 with great success in an enviroment of high level scientific quality and great cordiality. The meeting had the academic support of the Argentine Society of Cancerology (SAC-AMA) and the Argentine Society of Oncological Radiation Therapy (SATRO). It was also an honour to receive the official support of the Government of the State of Mendoza.

The objective of Brain Tumor Awareness Day in our country is to increase visibility of this illness in order to improve early diagnosis and treatments, encourage the formation of interdisciplinary teams around the country, and understand that this is the best way to approach the challenges of brain tumours. During the meeting, information was provided and a lively exchange of experiences, advances and discussion of results took place.

Additionally, the meeting encouraged more research and the use of technology.

We would like to thank members of our AANC Section on Tumors, national and international guests, and all young residents, who have generously participated in the 9th Brain Tumor Awareness Day in Argentina. ■

New beginnings: Meagan's HUG

Elizabeth Becker

Head of Support, Meagan's Hug

Paediatric brain tumour researcher Taylor Bridge with Meagan's Hug Hero, Cierra, pictured at age 5

Photo by Gordon Cheong

For over 19 years Canada-based Meagan's Walk: Creating a Circle of Hope has been a driver for change in the care of children affected by a brain tumour diagnosis. With a focus on raising funds for life-changing paediatric brain tumour research, this community based not-for-profit organization, Meagan's Walk, working with dedicated and talented volunteers, has directed over CAD $5.8 million to paediatric brain tumour research through SickKids Foundation in Toronto.

On September 1st, 2020 Meagan's Walk took its first steps with a new look and name: Meagan's HUG: Creating a Circle of Hope. And these changes marked as well its new beginning as an independent charity with a Canada Revenue Agency registered charity number.

Why Meagan's HUG? In late 2000 little Meagan Bebenek was diagnosed with DIPG, an inoperable and malignant brain tumour. She died six months later, on June 17th, 2001, only two weeks past her fifth birthday.

That June day, leaving Meagan at SickKids, Denise, Meagan's mother, envisaged a real yet symbolic "hug" of the hospital, sending a message to all within that they are not alone. This vision became an annual Walk and Hug event, with thousands joining in every year to form this hand in hand "circle of hope". Well known across Canada, Meagan's Walk draws people from Toronto, across Ontario and well beyond. And, over the years, the 'hug" has become its enduring signature, and now its name.

This hug has inspired an outpouring of support from the community, with community events raising funds and awareness for its purpose. These continue, as well as the Meagan's Walk "Kids Helping Kids" vibrant school program that is part of the curriculum for one of the largest school boards in Canada, as well as in other schools. The program empowers young people to make a difference and foster compassion within their own school communities, and provides leadership opportunities.

As Denise, Founder and Chair, shepherds the organization into this new beginning, her vision endures and is unchanged. Meagan's Hug looks forward to continuing and nurturing its mutually respectful and beneficial relationship with SickKids and the Brain Tumour Research Centre in Toronto, sharing dreams and goals.

The Meagan Bebenek Endowment Fund continues to grow, providing in perpetuity, financial resources to support research. This will continue.

Some seven years ago, the Meagan's Walk Neuro-oncology Fellowship began. Funded fully by the Endowment, the Fellowship brings clinical researchers from around the world to train in Toronto with one of the world's largest paediatric brain tumour programs at SickKids. The Fellowship continues, along with the funding of seed research projects, some of which have resulted over the years in seminal discoveries; the establishment of clinical trials; and the purchase of cutting edge equipment.

Says Denise: "I imagine a world full of possibilities and greater achievements, as researchers and clinicians around the globe work in collaboration to make their dreams reality. I am confident Meagan's HUG will continue to open doors."

The need for ground-breaking and life-changing brain tumour research is as important as ever! ■

For more information about Meagan's Hug, please visit meaganshug.com

Walking together in 2019 in hope and celebration

In 2019, more than 10,000 people took part in 22 awareness-raising walks across Canada to raise funds for Brain Tumour Foundation of Canada and raised a staggering $1.85 million (CAD) to help in the battle against brain tumours. Here are a few photo memories of some of these walks. ■

London, Ontario Brain Tumour Walk, 2019

Right: Abbey and Tom made Brain Tumour Foundation of Canada history by becoming the first couple to get engaged at a Brain Tumour Walk in Yellowknife, Northwest Territories, in 2019.

Far right: 25-year survivor Barb Clark said the walks are like Christmas Day – a time for family, friends, and happiness.

IHI A RANGI
NZ Brain Tumour Trust

NZBTT is a charitable trust which recognises the need for patient and research support in New Zealand, and aims to make a real and positive difference to the lives of people of all ages diagnosed with a brain tumour.

The Trust seeks to promote a culture of healing, wellbeing, and support at all stages of an individuals' experience with a brain tumour, both cancerous and benign, also supporting their family and whānau.

The Trust also aims to help brain tumour patients by underwriting research, providing funding, and encouraging the newest therapies to New Zealand through clinical trials.

Through Ihi a Rangi New Zealand Brain Tumour Trust, we seek to bring the promise of better therapies, care, and cure.

@nzbraintumourtrust www.nzbtt.org.nz

From a handpainted original by a Brain Tumour Survivor

Brain Tumour Foundation of India

Detection • Treatment • Rehabilitation • Care • Support • Hope

www.braintumourindia.org

1129, Homi Bhabha Block, Tata Memorial Hospital,
Parel, Mumbai - 400012, INDIA. Email: btf@braintumourindia.org

CBTA Childhood Brain Tumor Association of Taiwan

We are Childhood Brain Tumor Association of Taiwan

Our mission is to help brain tumor children to improve a better quality of life.

Comfort access
Family Care
School Education Support
Vocational Training
Grief counseling
Information exchange

For more information, visit:

www.cbta.org.tw
cbta.taiwan@msa.hinet.net
www.facebook.com/cbta.org.tw/

astro brain tumour fund

Charity No. 113356

FINDING A CURE FOR BRAIN TUMOURS

Funding research and offering information, inspiration and hope for those affected by slow-growing brain tumours.

Low-grade brain tumours can lie undetected for many years before symptoms suddenly appear and turn victims' lives upside down.

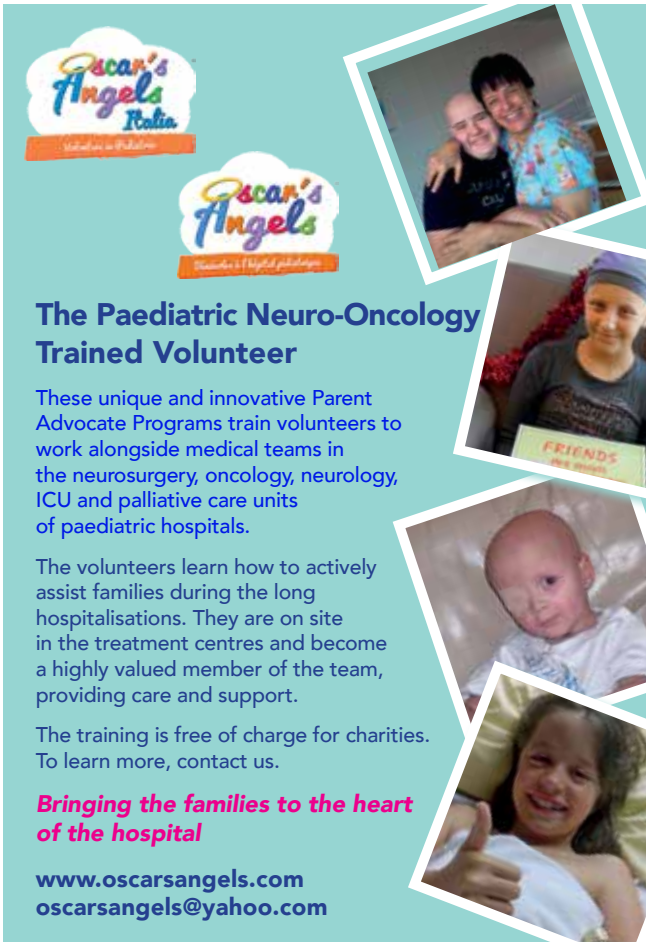
They cause progressive mental and physical problems, and sometimes transform to a more malignant form of brain tumour.

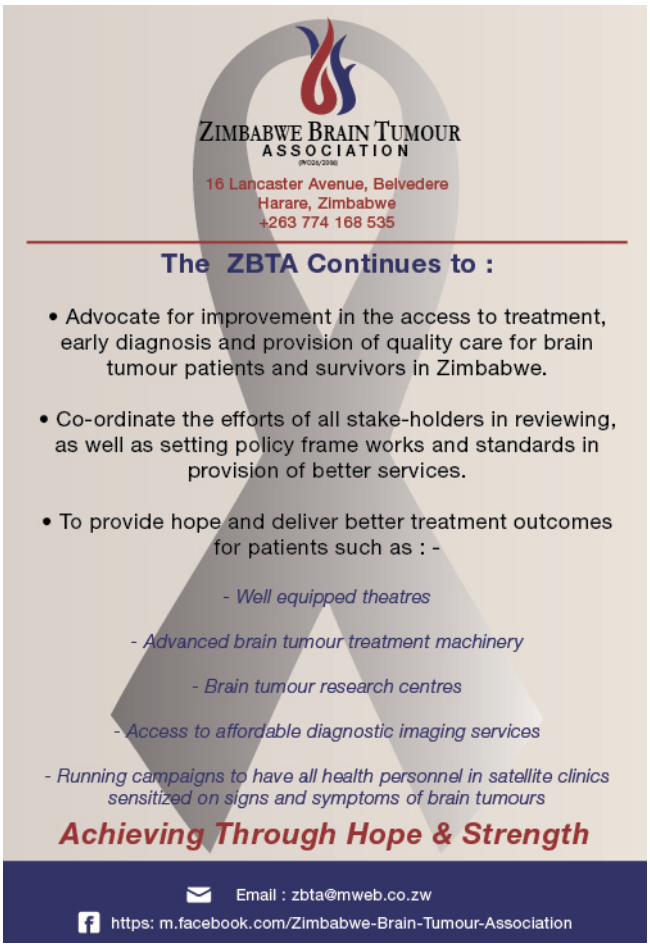
Astro Brain Tumour Fund is working hard to end the anguish for those living with this devastating form of cancer by funding research in the UK and providing a Facebook support group for patients and carers.

For more details, please contact
Mary on **01485 52 52 79**
treasurer@astrofund.org.uk
Linda on **02084 05 88 53**
lindatrustee@astrofund.org.uk
or browse our website at **www.astrofund.org.uk**


Fondo Alicia Pueyo
For research on children's brainstem gliomas
Fighting Diffuse Instrinsic Pontine Gliomas
Funding research on brainsteam gliomas
Supporting Families fighting this terrible disease
Promoting international collaboration to find a cure
Current Research Project:
New clinical trial with autologous dendritic cells pulsed with tumoral cell-lines lysate
Institution:
Hospital Sant Joan de Déu (Barcelona, Spain)
www.fondoaliciapueyo.org
info@fondoaliciapueyo.org
c/Santa Rosa, 39,-57 08950
Esplugues de Llobregat
Barcelona
Collaborations needed to fund this project
Those interested, contact
ggarciaca@sjdhospitalbarcelona.org


hersentumor contactgroep
hersenletsel.nl
Supportgroup Braintumors
The Netherlands
www.hersenletsel.nl/over-ons/werkgroepen/hersentumor-contactgroep
johndebruin@hersenletsel.nl
jelledevries@hersenletsel.nl


Oscar's Angels Italia
Oscar's Angels
The Paediatric Neuro-Oncology Trained Volunteer
These unique and innovative Parent Advocate Programs train volunteers to work alongside medical teams in the neurosurgery, oncology, neurology, ICU and palliative care units of paediatric hospitals.
The volunteers learn how to actively assist families during the long hospitalisations. They are on site in the treatment centres and become a highly valued member of the team, providing care and support.
The training is free of charge for charities. To learn more, contact us.
Bringing the families to the heart of the hospital
www.oscarsangels.com
oscarsangels@yahoo.com


Zimbabwe Brain Tumour Association
16 Lancaster Avenue, Belvedere
Harare, Zimbabwe
+263 774 168 535
The ZBTA Continues to :
• Advocate for improvement in the access to treatment, early diagnosis and provision of quality care for brain tumour patients and survivors in Zimbabwe.
• Co-ordinate the efforts of all stake-holders in reviewing, as well as setting policy frame works and standards in provision of better services.
• To provide hope and deliver better treatment outcomes for patients such as : -
- Well equipped theatres
- Advanced brain tumour treatment machinery
- Brain tumour research centres
- Access to affordable diagnostic imaging services
- Running campaigns to have all health personnel in satellite clinics sensitized on signs and symptoms of brain tumours
Achieving Through Hope & Strength
Email : zbta@mweb.co.zw
https: m.facebook.com/Zimbabwe-Brain-Tumour-Association

GLIOTRAIN: A multi-pronged attack on glioblastoma

Dr Alice O'Farrell
GLIOTRAIN Research Programme Manager

Prof Annette Byrne
GLIOTRAIN Co-ordinator, Royal College of Surgeons in Ireland

In the last edition of 'Brain Tumour' magazine, we introduced readers to the GLIOTRAIN PhD students and to the research that they are undertaking within the international project, focused on glioblastoma (GBM). Here, the GLIOTRAIN consortium (coordinated by Prof Annette Byrne of the Royal College of Surgeons in Ireland) brings us up-to-date on the consortium's research.

The GLIOTRAIN project (www.gliotrain.eu) is an EU funded Marie Skłodowska Curie Innovative Training Networks (ITN) award recipient coordinated by the Royal College of Surgeons in Ireland. The four year project received funding of almost €3.9 million from the European Commission's Horizon 2020 Research and Innovation Framework Programme and commenced in September 2017. This major research initiative, which is training the next generation of brain cancer researchers, has now reached the end of its third year and we are pleased to provide you with an update on our work to date.

The research objective of GLIOTRAIN is to identify novel therapeutic strategies for treating GBM patients, while implementing state of the art methods to unravel disease resistance mechanisms. Ultimately the aim of GLIOTRAIN is improved patient outcomes from this most difficult to treat disease.

Since the last publication of *Brain Tumour*, GLIOTRAIN passed its half-way point, which is a key milestone for ITN projects. A substantial report was submitted to the European Commission in October 2019, containing information regarding student training and scientific research. The report was evaluated and approved in December 2019. The second GLIOTRAIN annual meeting also took place at the University of Stuttgart, Germany in October 2019. All 15 students had the opportunity to present their projects and undertake discussions with the full consortium. A training event for our students, focusing on systems biology and data modelling was also held at this time.

GLIOTRAIN has been no exception when it comes to the impact of the COVID-19 pandemic, which has affected our project in a number of ways since March 2020. Nevertheless, all of our students have worked through this very difficult time superbly, following guidance from the European Commission and all national rules and guidelines. It has been a challenging time for some, especially for those students who work predominantly in laboratories, as well as those who are isolated from their friends and families, often not even in their home countries. Where possible some laboratory research work has continued, albeit in a much reduced capacity, but we hope that in the coming months the project will continue in the "new normal".

Key scientific accomplishments

Since our last article, the consortium has accomplished some key scientific milestones. A priority in mid-2019 was to collate samples for the GLIOTRAIN biobank. A biobank is a collection of biological samples and matched clinical follow up data for use in research. The GLIOTRAIN biobank cohort consists of GBM tumour samples from biorepositories in The Netherlands, France, Luxembourg and Ireland.

The consortium ensured that the tissue and patient data (always de-identified) had been collected ethically (with informed consent of the patient), to make sure that it is handled appropriately and to ensure confidentiality. All of the tissue samples underwent genetic sequencing: specifically, whole genome sequencing (WGS) and RNA sequencing, whilst some of the samples (representing short- medium- and long-term patient survival) were chosen for DNA methylation analysis. WGS reveals the frequency of mutations in the tumour DNA; cancerous tissue is usually more genetically unstable that normal tissue and has higher levels of mutation (e.g. multiple copies of some genes and loss of others). RNA sequencing is used to investigate specific genes that are being over- or under-expressed by the GBM tumours. Finally, DNA methylation is a biological process that can change the activity of a DNA segment without changing the DNA sequence. Alterations in DNA methylation, that may lead to inappropriate "gene silencing", have been recognised as an important component of cancer development (Jones and Baylin Nat Rev Genet. 2002 Jun;3(6):415-28.).

All samples were also analysed for their expression of a large number of proteins

that are commonly dysregulated in cancer. Proteins are large molecules present inside cells that carry out the instructions given by the DNA and RNA. They are essential parts of organisms and participate in virtually every process within cells. Small changes in protein expression can lead to disease, including cancer.

Comparing the differences in DNA, RNA, methylation and protein profiles between tumours from different patients can indicate how they might react differently to different treatments or why some patients may have a better prognosis than others. These differences may also provide clues as to what might be a suitable "target" for new treatments. For example, grouping patients according to the mutation "map" or the specific gene, methylation or protein expression patterns of their tumour may enable researchers to identify new targets of vulnerability for specific patients. This would also drive the development of new therapeutic options for GBM patients and would underpin a more stratified clinical trial approach. An example of where this might be key is in the area of immuno-therapy, which to date has been disappointing in GBM. However, using immune specific signatures generated from sequencing of a patient's tumour might identify individual patients who would benefit from such drugs. Finally, comparing the differences between tumours of patients who were known to have survived for longer may provide some insight into the biology of GBM tumours that are more or less aggressive. Several GLIOTRAIN PhD students are working on projects to address these questions.

The tumour microenvironment (TME) is the cellular environment in which the tumour exists, including surrounding blood vessels, white blood cells and other cells which interact with the tumour. This complex cellular ecosystem contributes to the diversity (heterogeneity) shown by GBM tumours. A number of our PhD students work on projects that use highly innovative single-cell sequencing techniques to study this environment, which will provide information on how therapies might affect patients differently, depending on their TME.

Elsewhere, GLIOTRAIN students are working hard to identify new treatment options for primary and recurrent GBM (e.g. development of novel drugs, re-purposing of currently available drugs) and to improve delivery of therapeutic agents, including immunotherapies, to the brain. The transport of drugs from the blood stream to a GBM tumour is hindered by the presence of the blood brain barrier. This is a barrier of cells that usually protects the brain from harmful chemicals in the blood, but in the context of treatment can limit or even totally obstruct a drug reaching its target.

Finally, we have students using machine learning and mathematical modelling methods to attempt to unravel the resistance mechanisms in GBM. These projects are also modelling possible mechanisms of how to overcome such resistance. This is important, given that the insufficient life-expectancy of most GBM patients is driven largely by the development of resistance to treatment.

The GLIOTRAIN consortium at the 2nd annual meeting, which took place at the University of Stuttgart in October 2019. Pictured are: Prof Annette Byrne (GLIOTRAIN Coordinator & Principle Investigator [PI]), Dr Alice O'Farrell (GLIOTRAIN Programme Manager), **PIs and postdoctoral researchers:** Dr Brona Murphy, Prof Markus Morrison Rehm, Dr Gavin Fullstone, Dr Maite Verreault, Dr Kate Connor, Prof Martine Lamfers, Prof Jochen Prehn, Dr Manuela Salvucci, Dr Marc Sturrock, Dr Anna Golebiewska, Prof Sieger Leenstra, Dr Andreas Kremer, Prof Reinhard Schneider, Mr Philip Stegmaier and Mr Cristiano Guttà. **GLIOTRAIN PhD Students:** Viktorija Juric, Chiara Boccellato, Nivetha Krishna Moorthy, Mohammed Ahmed, Kieron White, Jenny Weng, Ioannis Ntafoulis, Gonca Dilcan, Archita Biswas, Ayoub Lasri, Francesca Lodi, Yahaya Yabo, Federica Fabro, Manasa Kalya Purushothama and Romain Tching Chi Yen. Not pictured: Nivetha Krishna Moorthy and Mohammed Ahmed

A multi-pronged attack on GBM

Overall, GLIOTRAIN employs multiple strategies towards our overall research objective to ➤

CAPTION: GLIOTRAIN PhD student Francesca Lodi working in Belgium during the COVID-19 lockdown (April 2020)

identify novel therapeutic approaches to improve GBM patient outcomes. Recently generated data will be further developed, and key findings validated and disseminated in the coming year.

Importantly, several members of the consortium have recently published a state of the art position paper (https://www.annalsofoncology.org/article/S0923-7534(20)42428-7/fulltext) discussing novel treatment approaches and ongoing trials in the IDH-wildtype GBM setting. In this paper, we propose an integrated drug discovery stratagem incorporating multi-omics, single cell technologies and computational approaches to advance the field and provide novel therapeutic targets and treatments, with an overall goal to improve GBM patient outcomes.

The GLIOTRAIN consortium gratefully acknowledges patients who kindly donated tumour tissue and clinical data, thus making the project possible.

The consortium further acknowledges contributions from the Clinical and Epidemiological Investigation Center, Department of Population Health, Luxembourg Institute of Health in support of the LIH Brain Tumour Resource and funding received from Brain Tumour Ireland in support of the Beaumont Hospital Brain Tumour Bioresource. As always, we would also like to extend our gratitude to the IBTA and Kathy Oliver for their ongoing support. ■

For more information on GLIOTRAIN, links to recent scientific publications and our Newsletters, please visit our website: www.gliotrain.eu. For regular updates on what our students are up to follow us on Twitter (@gliotrain) and Facebook (@GliotrainEU).

GLIOTRAIN has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie ITN initiative (Grant Agreement # 766069). The material presented and views expressed here are the responsibility of the author(s) only. The EU Commission takes no responsibility for any use made of the information set out.

The Pediatric Brain Tumor Foundation's mission is simple, yet powerful:

CARE. CURE. THRIVE.

Since 1991, the Pediatric Brain Tumor Foundation has partnered with organizations to fund more than $45.7 million in research. Today, we are leading the way in transforming how pediatric brain tumors are treated and children and teens are cared for.

CARE. PBTF is the first point of contact for newly diagnosed families, empowering them with emotional, informational and financial support.

CURE. PBTF provides critical funding to address key gaps in the research pipeline, accelerate therapies and cure all childhood brain tumors.

THRIVE. PBTF offers a thriving community of support for families in need, walking alongside them from diagnosis through treatment and beyond.

A world without childhood brain tumors IS possible. Join us in the fight to CARE, CURE and THRIVE.

Pediatric Brain Tumor Foundation

www.curethekids.org
info@curethekids.org

http://gfmefree.fr

GFME 19 years

GFME, **Glioblastoma Fundation Michele Esnault**, established in **2001** is a French-based (Marseille), patient-oriented, support group involved in **brain tumors**. GFME translates and publishes in French **scientific publications** of Pubmed and **ASCO** on primary brain tumors. The association gives support, help, guidance on treatments and clinical trials for **adults and children** diagnosed with brain tumor. GFME works in partnership with ARTC, Brain Tumor Association For Research to rise funds. GFME is a website http://gfme.free.fr a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and two mailing-lists (gfme@yahoogroupes.fr and astrocytome-gfme@yahoogroupes.fr).The group includes **728 patients,** care givers**, friends and family members** around the globe. For more details gfme@free.fr

SWEDISH
BRAIN TUMOR
ASSOCIATION

We enhance quality of life – supporting brain tumour patients and care givers through support groups, events and lectures where we share with each other and learn about the disease.

We advocate – spreading information that may be helpful to anyone who needs facts about the disease and the patient and caregiver situation.

We promote more equal care – contributing to keeping the national care programs constantly updated so that the best care and treatment methods are available to all brain tumor patients, regardless of their place of residence.

We follow the research internationally – in constant dialogue with healthcare professionals, researchers, healthcare policy and other decision makers.

For more information visit us on our website:
www.hjarntumorforeningen.se
You can also find us on Facebook and Messenger:
facebook.com/hjarntumorforeningen

BRAIN TUMOUR INFORMATION & SUPPORT

BRAINWAVES NI

Supporting Children and Adults affected by
Brain Tumours in Northern Ireland

Recently Diagnosed or Living with a Brain Tumour?

We are here to Help...

Contact **Information** **Support**

Call: **028 8676 6000** or email: **info@brainwaves-ni.org**
35 Loy Street, Cookstown, Co. Tyrone, BT80 8PZ

www.brainwaves-ni.org | Find us on:

Registered Charity No: NIC103464 Registered with The Charity Commission for Northern Ireland

WE CAN MAKE A DIFFERENCE!

San Diego Brain Tumor FOUNDATION

Supporting the Needs of Patients & Families

The San Diego Brain Tumor Foundation (SDBTF) is here to Support the Needs of Patients and their Families. We make a difference in the San Diego Community by helping patients and their families cope with having a brain tumor.

We hold monthly support groups and provide financial assistance to those that cannot work and need help in paying their monthly rent or mortgage, their medical bills, and provide groceries and gas cards to families as needed.

If you are a patient, a caregiver, or a friend
call: **(619) 515-9908** or email: **info@sdbtf.org**

www.sdbtf.org

JACOB'S HOPE FOUNDATION

- We are a new advocacy organisation for brain tumour patients and people with other cancers in Cameroon, Africa.
- We educate survivors and caregivers on nutrition and quality of life.
- We help establish advocacy groups in our country.
- We provide information and raise awareness of the challenges of brain tumours and other cancers in our Cameroonian society by using colourful visuals so that people can absorb and remember information which will help them.
- We have a Facebook page - search for Jacob's Hope Foundation

You can phone us on 00237 677 344 981
You can email us at: ngong.irene@gmail.com

brainstrust
the brain cancer people

Here to help you live life with a brain tumour.

Receive tailored support, 24/7, whether you are a patient, carer or loved one.

Access resources and workshops to help you live better with a brain tumour.

Meet a community of people that understand life after diagnosis.

We know.

Not knowing what the future holds.

Call our 24/7 support line on **01983 292 405**
email **hello@brainstrust.org.uk**
or visit **brainstrust.org.uk**

Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642).

GliMR - shedding light on advanced MRI imaging for glioma

Esther Warnert, PhD

Chair of GliMR, Department of Radiology & Nuclear Medicine, Erasmus MC, Rotterdam, the Netherlands

Patricia Clement, MSc

Chair of Dissemination Working Group GliMR, Ghent Institute for metabolic and Functional Imaging (GIfMI), Ghent University, Belgium

In Europe, approximately 50,000 new cases of glioma, including glioblastoma, occur each year, and this number is expected to rise with the ageing population. Well-established international consortia are putting tremendous research efforts into a better understanding of glioma pathology and improved treatment strategies.

Magnetic resonance imaging (MRI) only has a minor role in these research efforts, despite being a widely available medical imaging modality and whilst advanced MRI techniques are emerging with great potential for improved characterisation of glioma. To exploit advanced MRI to the fullest, two issues need to be solved:

1. **The scattered research landscape in which advanced MRI is being developed for glioma imaging**
2. **The limited presence of advanced MRI research in established (international) networks for clinical work and research in glioma**

To tackle the above issues a group of European researchers came together in early 2018 to start connecting the imaging and non-imaging communities focused on glioma research and clinical practice. This led to funding obtained from the European Commission in the summer of 2019, which kick-started the European COST Action* "Glioma MR Imaging 2.0", or for short - GliMR.

This COST Action received funding for four years (September 2019 to September 2023) and aims to unite the glioma imaging and non-imaging community such that advanced MRI techniques will be further developed and used for improved decision making in diagnosis, patient monitoring, and assessment of treatment response in clinical trials and clinical practice. At present GliMR connects over 150 clinicians, researchers, representatives of patient organisations and related stakeholders from 30 countries**.

GliMR is structured in five working groups, each with its own specific focus and aims and

Participants at the first annual GliMR meeting in Malta – December 2019

The first kick-off meeting of the GLIMR management committee in Brussels, September 2019.

milestones, but all collaborating to achieve the main goal of the Action.

- 'Advanced MRI biomarkers for glioma characterisation' focusses on the coordination of the identification and quantification of advanced MRI biomarkers for application in glioma.
- 'Multi-site data integration' coordinates the development of tools and guidelines for multi-site data integration which will enable the creation of large datasets in glioma diagnostics.
- 'Clinical translation' fosters cross-border information exchange of past, current, and future clinical glioma trials and studies.
- 'Stakeholder relations' ensures representation of all relevant stakeholders within GliMR, initiates collaborations with stakeholders inside and outside the network, and coordinates the communication between all stakeholders.
- 'Dissemination' supports the other working groups in the dissemination of their goals and results, in tailored manners to the research community in- and outside this Action, clinical practice, patient organisations, as well as the general public.

We are an active network and are always looking forward to welcoming new members. For more information about GliMR and how to join please visit our website www.glimr.eu. Here you will also be able to subscribe to our bi-monthly newsletter and there are links to our Twitter and Instagram accounts. ■

*The European Cooperation in Science and Technology (COST) is a funding organisation for the creation of research networks. More information about COST itself can be found on www.cost.eu

** Austria, Belgium, Bosnia and Herzegovina, Bulgaria, Canada, Croatia, Cyprus, Czech Republic, Denmark, Estonia, France, Germany, Greece, Ireland, Italy, North Macedonia, Malta, Morocco, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Spain, Switzerland, The Netherlands, Turkey, United Kingdom, United States.

The IBTA maintains a list of key online clinical trials portals to help patients and caregivers locate clinical trial centres and understand criteria for joining a brain tumour trial.

For more information, visit www.theibta.org

PBTN Pediatric Brain Tumour Network JAPAN

We are the network of groups of the pediatric brain tumour patients and their families in Japan, who help each other to improve our quality of life through peer support and discussion on our web site, through organising a summer camp and by appealing to the government etc.
For more information, see the website addresses below.

Child Brain Tumor Parents Support Group
http://www.pbtn.jp

"Child Brain Stem Glioma Network"
http://glioma-net.com/page6

"cranio park"
(for craniopharyngioma patients and families)
http://cranio-park.fc2-rentalserver.com/

Pediatric Brain Tumour Support Group in Kinki prefecture
http://miracle-brain.jimdo.com/

Japan Brain Tumour Alliance (JBTA)
http://www.jbta.net/

CBTA
CYPRUS BRAIN TUMOUR ASSOCIATION
ΚΥΠΡΙΑΚΟΣ ΣΥΝΔΕΣΜΟΣ ΦΙΛΩΝ ΚΑΙ ΑΤΟΜΩΝ ΜΕ ΟΓΚΟΥΣ ΕΓΚΕΦΑΛΟΥ

Cyprus Brain Tumour Association

- Offers Support and encouragement to brain tumour patients and their families
- Aims to achieve recognition of the specific challenges brain tumour patients and their carers face in dealing with the disease
- Gives information for brain tumour patients to assist making treatment decisions
- Supports research for the development of more

Tel.: 0035799616113
Email: cybraintumour@hotmail.com / sotosol@cytanet.com.cy

4B Agiou Damianou Street • 2054, Archangelos • Nicosia • Cyprus
Facebook: Cyprus Brain Tumour Association

PHILIPPINES BRAIN TUMOR ALLIANCE

* FOUNDING DIRECTORS *
William Abbott-GBM survivor 13 yrs: Susan Abbott

** VOLUNTEERS **
Isa Pangilinan, Chris Locher

*** MEDICAL ADVISERS***
Dr. Gerardo Legaspi, Dr. Santosh Kesari, Dr. Marlon Saria
Dr. Gerry Cornelio, Dr. Steven Bacalian, Dr. Roland Gigataras
Dr. Louie Gayao, Dr. Powix Villamor Jr.

BID Compound, Gov. I. Santiago Street
Malinta, Valenzuela City, Metro Manila 1140, PHILIPPINES
FACE BOOK: Philippines Brain Tumor Alliance
Tel. #: +632 8294 6275. Cellphone #: +63 916 777 9435
E-mail: pbta.wilabbott@gmail.com, pbta.sueabbott@gmail.com

Brain tumours kill more children and adults under the age of 40 than any other cancer

Just 1% of the national spend on cancer research has been allocated to this devastating disease

Brain Tumour Research is determined to change this.

We are building a network of experts in sustainable research at dedicated UK Centres of Excellence whilst influencing the UK Governments and larger cancer charities to invest more nationally.

Please help us fund the fight.

Together we will find a cure

Email: info@braintumourresearch.org
www.braintumourresearch.org
Tel: +44 (0)1908 867200

Brain Tumour Research

Registered charity number 1153487 (England and Wales)
SC046840 (Scotland). Company limited by guarantee number 08570737.

Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

AUSTRALIA

ACT Brain Tumour Network
Email btaa@shout.org.au
or call Susan on 0404255156

Adult Brain Cancer Support Association
adultbraincancersa@gmail.com https://www.facebook.com/AdultBrainCancerSA?fref=nf

Australian Pituitary Foundation
http://www.pituitary.asn.au/

Brain Tumour AhoyHoy
http://www.braintumourahoyhoy.org/

Brain Tumour Alliance Australia (BTAA)
www.btaa.org.au

Brain Tumour Association Western Australia
braintumourwa@hotmail.com
http://www.btawa.com.au/

Brain Tumour Support Group - Cancer Council Queensland
https://cancerqld.org.au/get-support/
or https://cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support/

Cure Brain Cancer Foundation
http://www.curebraincancer.org.au

Grey Matters
www.greymatters.org.au

Mark Hughes Foundation
https://markhughesfoundation.com.au/

Neuro-Oncology Information Network - NOgIN
http://www.sydneybrainandspinesurgeons.com.au/nogin.html

Newro Foundation
http://www.newrofoundation.com.au/

Peace of Mind Foundation
http://www.peaceofmindfoundation.org.au

Robert Connor Dawes Fund
http://rcdfoundation.org/

United Brain Tumour Support
Contact Pete McLaughlin:
(Australia) 0422 784885.
Listing here also: http://www.yourcare.com.au/supplier/profile/united-brain-tumour-support

BELGIUM

Can cé tu
http://www.cance-tu-asbl.eu

Werkgroep Hersentumoren
http://www.wg-hersentumoren.be

CAMEROON

Jacob's Hope Foundation
https://www.facebook.com/Jacobs-Hope-Foundation-for-Brain-tumours-and-other-cancers-1735452683351613/

CANADA

BC Cancer Agency
http://www.bccancer.bc.ca

B-Strong
http://www.bstrong.ca

b.r.a.i.n.child
http://www.sickkids.ca/Brainchild/index.html

Brain Tumour Foundation of Canada
www.braintumour.ca

Gerry and Nancy Pencer Brain Tumor Centre
http://www.pencerbraintrust.com/

Meagan's HUG
https://www.meaganshug.com/

Tali's Fund
www.taldoron.com

CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands) "The Forgotten"
https://www.facebook.com/pg/bftcaymanislands/posts/

CROATIA

Croatian Brain Tumor Association - GLIA
www.glia.hr

CYPRUS

Cyprus Brain Tumour Association (CBTA)
https://www.facebook.com/cbta.cyprus

DENMARK

HjernetumorForeningen
http://www.cancer.dk/hjernetumorforeningen/

FRANCE

Alinoe (Association Lilloise de Neuro-Oncologie)
www.alinoe.asso.fr

ARTC Paris
http://www.artc.asso.fr/

ARTC Sud
www.artcsud.fr

ARTC Toulouse – Midi Pyrenees
http://www.artc.asso.fr

Association Léa Princesse Eternelle
http://leapourlavie.free.fr/

GFME Glioblastoma Fundation Michèle Esnault
http://gfme.free.fr/

Imagine for Margo
http://imagineformargo.org/en

Oligocyte Bretagne Ouest
https://assoligocyte.wordpress.com/association/

Oscar's Angels
www.oscarsangels.com

GERMANY

Deutsche Hirntumorhilfe eV
www.hirntumorhilfe.de

INDIA

Brain Tumour Foundation of India
www.braintumourindia.org

BTSG Awareness Foundation India (Brain Tumor Support Group and Awareness Foundation)
www.btsgfoundation.in

IRELAND

Brain Tumour Ireland
http://www.braintumourireland.com/bti/

The Irish Brain Tumour Support Group
www.braintumoursupport.ie

ITALY

Associazione Italiana Tumori Cerebrali ONLUS
http://www.tumoricerebrali.it/

BrainLife
www.brainlife.org

Il Fondo di Gio ONLUS
www.ilfondodigio.it

IRENE Onlus
http://www.associazioneirene.it/

Italia - Glioblastoma Multiforme - cancro al cervello
https://www.facebook.com/Italia-Glioblastoma-multiforme-cancro-al-cervello-57560022151/

Oscar's Angels Italia
https://www.oscarsangelsitalia.com

JAPAN

Japan Pediatric Brain Tumor Network
www2.pbtn.jp

Japan Brain Tumor Alliance
http://www.jbta.org

LEBANON

CHANCE - Children AgaiNst CancEr
http://www.beirut.com/l/25407

LITHUANIA

Kartu Lengviau
www.kartulengviau.lt/joomla/pradzia.html

Lithuanian Brain Tumour Patients and their Caregivers Society
Phone: +370 37 326694

NETHERLANDS

Hersentletsel.nl
http://www.hersenletsel.nl

Hersentumor.nl
http://hersentumor.nl/

STOPhersentumoren.nl
www.stophersentumoren.nl

NORWAY

Hjernesvulstforeningen
www.hjernesvulst.no

PAKISTAN

Brain Tumour Foundation of Pakistan In partnership with the Pakistan Society of Neuro-Oncology
www.braintumour.pk

PHILIPPINES

Philippines Brain Tumour Alliance
http://www.facebook.com/pages/Philippine-Brain-Tumor-Alliance/139492062749160/

SINGAPORE

Brain Tumour Society (Singapore)
http://braintumoursociety.org.sg

SOUTH AFRICA

Rainbows and Smiles
http://www.rainbowsandsmiles.org.za

SPAIN

Association Española de Afectados por Tumores Cerebrales - ASATE
http://www.asate.es/

Fondo Alicia Pueyo - The Alicia Pueyo Fund
www.fondoaliciapueyo.org

SWEDEN

Swedish Brain Tumor Association (Svenska hjärntumörföreningen)
www.hjarntumorforeningen.se

SWITZERLAND

Kinderkrebs Schweiz
http://www.kinderkrebshilfe.ch

Schweizer Hirntumor Stiftung (Swiss Brain Tumor Foundation)
http://www.swissbraintumorfoundation.com

TAIWAN

Childhood Brain Tumour Association of Taiwan (CBTA)
http://www.cbta.org.tw

TURKEY

Turkiye Beyin Tumoru Hasta ve Yakinlari Dernegi (Brain Tumour Patient & Caregivers' Association of Turkey)
https://www.facebook.com/tbthyd/

UGANDA

Uganda Brain Tumour Foundation
http://www.ubtuf.org

UNITED KINGDOM

Ali's Dream
www.alisdream.co.uk

Andrew McCartney Trust Fund
www.andrewmccartneyphotos.co.uk

Anna's Hope
www.annashope.co.uk

Astro Brain Tumour Fund
www.astrofund.org.uk

Brain and Spine Foundation
www.brainandspine.org.uk

Brain Tumour Action
www.braintumouraction.org.uk

Brain Tumour Research
www.braintumourresearch.org

Brain Tumour Research and Support Across Yorkshire
http://www.btrs.org.uk

Brain Tumour Research Campaign
http://www.wayahead-btrc.org/

Brain Tumour Support
www.braintumoursupport.co.uk

Brain Tumour Support Group - St Thomas' Hospital, London
http://www.guysandstthomas.nhs.uk/our-services/cancer/cancer-types/brain/patients.aspx

Brainstrust
www.brainstrust.org.uk

Brainwaves Brain Tumour Support Group
http://www.brainwavessg.co.uk/

Brainwaves NI (Northern Ireland)
www.brainwaves-ni.org

British Acoustic Neuroma Association - BANA
www.bana-uk.com

Clowns in the Sky
http://www.clownsinthesky.org/

East Kent Brain Tumour Support Group
https://www.facebook.com/EKBTSG/

Ellie's Fund - Brain Tumour Trust
www.elliesfund.com

Fighting Ependymoma
http://www.fightingependymoma.org.uk

Headcase
www.headcase.org.uk

Katie McKerracher Trust
www.katiemckerrachertrust.co.uk

Levi's Star
http://www.freewebs.com/levisstar/

Naseem's Manx Brain Tumour Charity
http://www.naseemsmanxbraintumourcharity.co.uk/

PPR Foundation
http://www.thepprfoundation.com/

Spinal Cord Tumour Forum
www.spinalcordtumour.org.uk

Taylan's Project
www.taylansproject.com

Teenage Cancer Trust
www.teenagecancertrust.org

The Brain Tumour Charity
www.thebraintumourcharity.org

Thorne Mason Trust
http://www.thornemasontrust.co.uk/

Tuberous Sclerosis Association
www.tuberous-sclerosis.org

Worcestershire Brain Tumour Support Group
http://www.braintumoursupport.co.uk/worcestershire.html

UNITED STATES

Addi's Faith Foundation
www.addisfaithfoundation.org

Adult Ependymoma
https://sites.google.com/site/adultependymoma/

A Kid's Brain Tumor Cure (AKBTC)
http://akidsbraintumorcure.org

American Brain Tumor Association (ABTA)
www.abta.org

Angels Among Us
https://secure3.convio.net/dccc/site/TR/Angels/AngelsAmongUs?pg=entry&fr_id=1530

Ben and Catherine Ivy Foundation
www.ivyfoundation.org

Benny's World
http://www.bennysworld.org/

Brad Kaminsky Foundation
www.tbkf.org

Brain Candy Project
www.braincandyproject.org

Brain Science Foundation
www.brainsciencefoundation.org

Brain Tumor Foundation
www.braintumorfoundation.org

Brain Tumor Fund for the Carolinas
http://www.btfcnc.org/about/overview.cfm

Brain Tumor Network (BTN)
http://www.braintumornetwork.org

Brain Tumor Support Group of Northeast Florida http://resources.caregiver.com/listing/brain-tumor-support-group-of-northeast-florida.html

Brains Together for a Cure
www.brainstogetherforacure.org

Brian Bedell 2 Young Foundation
http://www.2yf.org

BT Survivor Online Group
www.btsurvivor.com

California Brain Tumor Association
https://www.facebook.com/The-California-Brain-Tumor-Association-217285898326170/

Central Brain Tumor Registry of the United States
http://www.cbtrus.org/

Central New Jersey Brain Tumor Support Group - CNJBTSG
www.njbt.org/startCNJBTSG.cfm

Childhood Brain Tumor Foundation
www.childhoodbraintumor.org

Children's Brain Tumor Foundation
www.cbtf.org

Chordoma Foundation
http://www.chordomafoundation.org

Collaborative Ependymoma Research Network (CERN) Foundation
http://cern-foundation.org

Cullather Brain Tumor Quality of Life Center
http://cullather.org/

Dr Marnie Rose Foundation
www.drmarnierose.org/
https://www.facebook.com/drmarnierosefoundation/

Emory Brain Tumor Support Group
www.neurosurgery.emory.edu/BTSG/contact.htm

EndBrainCancer (Chris Elliott Fund)
www.EndBrainCancer.org

Ependyparents online support group
http://braintrust.org/groups/ependyparents/

Epidermoid Brain Tumor Society (Online)
http://epidermoidbraintumorsociety.org/

Florida Brain Tumor Association
http://www.floridabraintumor.com/homepage.htm

Gray Matters Foundation
www.graymattersfoundation.com

Head for the Cure Foundation
www.headforthecure.org

Healing Exchange Brain Trust
http://braintrust.org

Jeffrey Thomas Hayden Foundation
www.jthf.org/

Just One More Day:
http://dipg.blogspot.co.uk/

Kevin J Mullin Memorial Fund for Brain Tumor Research
www.lemonhead.org/

Kortney Rose Foundation
http://thekortneyrosefoundation.org/

Lauren's Foundation
http://laurensfoundation.org/fitzys-5k-run/

Making Headway
www.makingheadway.org

Mark Linder Walk for the Mind
http://www.marklinderwalkforthemind.org/

mASS Kickers
http://www.masskickers.org/

Matthew Larson Pediatric Brain Tumor Research Foundation
www.ironmatt.org

Matthew's Miles
http://www.matthewsmiles.org/

Meningioma Mommas
www.meningiomamommas.org

Michael G Belz Foundation
http://mgbf.org

Michael Quinlan Brain Tumor Program/ Brain Injury Association of Kentucky
www.biak.us

Monmouth and Ocean County Brain Tumor Support Group
www.njbt.org/startMOCBTSG.cfm

Musella Foundation for Brain Tumor Research and Information, Inc.
www.virtualtrials.com

National Brain Tumor Society
www.braintumor.org

Nick Gonzalez Foundation for Brain Tumor Research
http://thenickgonzalesfoundation.org/

Oklahoma Brain Tumor Foundation
www.okbtf.org

Pediatric Brain Tumor Foundation
http://www.curethekids.org/

ROC On! Run Over Cancer
https://www.facebook.com/pages/category/Nonprofit-Organization/ROC-on-Run-Over-Cancer-310235803819/

San Diego Brain Tumor Foundation
www.sdbtf.org

Sontag Foundation
https://sontagfoundation.org

Southeastern Brain Tumor Foundation
http://sbtf.org/

Students Supporting Brain Tumor Research (SSBTR)
http://www.ssbtr.org/

Team Billy
www.teambilly.org

The Caroline Fund
http://www.carolinefund.org

The Cure Starts Now Foundation
www.thecurestartsnow.org

The Tanner Seebaum Foundation
www.tannersfoundation.org

Tug McGraw Foundation
http://www.tugmcgraw.org

Voices Against Brain Cancer
www.voicesagainstbraincancer.org

ZIMBABWE

Zimbabwe Brain Tumor Association (ZBTA)
https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/

Please join us in 2021!

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

30 October - 6 November 2021

The IBTA requires no financial commitment from your organisation to be a supporter.
Contact kathy@theibta.org

YOUR SUPPORT OF THIS POPULAR GLOBAL EVENT WILL FURTHER HELP BRAIN TUMOUR PATIENTS TO DEAL WITH THE CHALLENGES THEY FACE.

Thank you!

BRAIN TUMOURS:

MORE RESEARCH
MORE SUPPORT

IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE

www.theibta.org

theibta The International Brain Tumour Alliance