World Edition 2018/2019

INTERNATIONAL BRAIN TUMOUR ALLIANCE

Brain Tumour

You are not alone on this journey...

THE INTERNATIONAL BRAIN TUMOUR ALLIANCE...

building bridges to better outcomes for our patient and caregiver communities around the world

- Excerpts from the IBTA Summit and Sub-Saharan Africa conference reports
- All Aboard GLIOTRAIN!
- Predicting Risk of Post-Operative Cerebellar Mutism Syndrome
- The Neuro-Oncology Patient Survivorship Plan
- **AMGALAN**: a courageous, young Mongolian brain tumour hero
- Adult medulloblastoma - an orphan tumour
- Living with Li-Fraumeni Syndrome

PLUS:
Stories from our international brain tumour community: United States, Canada, United Kingdom, Australia, Japan, Colombia, Sri Lanka, Latin America, Europe and other regions

GREATER COLLABORATION ■ GREATER KNOWLEDGE ■ GREATER HOPE

Walk Around The World For Brain Tumours

a project of the

IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE

Walk Around the World for Brain Tumours!

Organise a sponsored walk to raise awareness of and funds for more research and support.

Walks can be done anytime between

1 January & 31 December 2018

The IBTA doesn't want any of your funds raised. These should go to local brain tumour support groups or relevant research institutions. We would like you to symbolically "donate" to the IBTA only the mileage achieved by you on your walk. Walks can also take place during the **International Brain Tumour Awareness Week (20 – 27 October 2018)** when groups and individuals around the world will organise scientific meetings, patient conferences, TV interviews, press releases, etc in order to raise awareness about brain tumours. For your organisation or group to be a "supporter" of the "Walk" and "Week" please contact the IBTA Chair as below. The IBTA requires no financial commitment or fee to be paid to us by you. All we are asking for is your enthusiasm in supporting and promoting these events and for allowing us to add your name to our list of supporters.

Top: Participants in the tenth anniversary Braintrekking Hong Kong walk in 2017
Above: A brain tumour survivor (blue tee shirt) walks in the Brain Tumour Foundation of Canada 2017 event in Edmonton, Alberta.

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

Contents

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International Brain Tumour Alliance (IBTA)
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Dear Reader,

Our latest edition of *Brain Tumour* magazine is literally bursting at the seams with great content.

We've included excerpts from two of the IBTA's major conference reports: the Sub-Saharan Africa Neuro-Oncology Collaborative ("S-SANOC") meeting held in partnership with the Society for Neuro-Oncology (SNO) and the Zimbabwe Brain Tumour Association (ZBTA), and the third biennial IBTA World Summit of Brain Tumour Patient Advocates which took place in London, UK in late 2017. The complete reports are freely available as digital copies from www.issuu.com (web links for the reports are provided on pages 12, 35, 96 and 120).

Also in this edition of *Brain Tumour* magazine are some incredibly inspirational articles from around the world about brain tumour patients and caregivers; researchers working tirelessly to find a cure; dedicated healthcare professionals and news of interest to the international brain tumour community.

As always, we are extremely grateful to everyone who has shared their stories of courage, dedication and discovery within these pages, providing those whose lives have been touched by a brain tumour with hope, wherever they live in the world.

With best wishes,

Kathy Oliver

Chair, International Brain Tumour Alliance (IBTA)

For extra single and bulk copies of *Brain Tumour* magazine and enquiries about postage and freight costs, or for enquiries about electronic versions of the magazine (including back issues), please contact kathy@theibta.org

Cover photograph by MVF Studios: Some of the participants at the third biennial World Summit of Brain Tumour Patient Advocates in London, UK, October 2017.

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

About the International Brain Tumour Alliance (IBTA)

The International Brain Tumour Alliance (IBTA) is a global network founded in 2005 as a dynamic worldwide community for brain tumour patient organisations, patients, caregivers and others involved in the field of neuro-oncology.

INTERNATIONAL BRAIN TUMOUR ALLIANCE

THE IBTA brings together experience and expertise from a wide range of stakeholders including patient organisations, researchers, healthcare professionals, government agencies, regulators, medical societies, key opinion leaders and others.
Our vision is a world free from the fear of brain tumours.
Our 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.

We work with Alliance supporters to:

ENCOURAGE
the establishment of brain tumour patient groups in countries where they don't yet exist;

PROMOTE
collaboration on programmes and projects to benefit the brain tumour community;

HIGHLIGHT
the challenges and needs of patients and caregivers;

DISSEMINATE
knowledge, information and best practice;

HELP
shape health and research policies at national and international levels;

HONOUR
the courage and achievements of brain tumour survivors and caregivers.

Through facilitating collaboration within the global brain tumour community, we provide a strong and collective voice for the brain tumour cause across the world.

Meet the IBTA team

Kathy Oliver is the IBTA's founding Co-Director and its Chair. She is based in Tadworth, Surrey, UK.

Gordon Oliver is a Co-Director of the IBTA and lives in Tadworth, Surrey, UK.

Chris Tse is an IBTA Senior Advisor. He lives in Wellington, New Zealand.

Sally Payne is an IBTA Senior Advisor based in Sydney, Australia.

Fraser Legge is the IBTA's financial administrator and is based in Edinburgh, UK.

Above: IBTA Directors and Advisors at the 2017 IBTA World Summit of Brain Tumour Patient Advocates, London, UK, October 2017

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My Inspirational and Courageous Son, Amgalan

Brain tumors know no geographic boundaries…

Naran Erdene

Mongolia

Above: Amgalan and his mother, Naran

I am Amgalan's mother.

Amgalan was born into our typical young Mongolian family and raised by us, his loving parents. Amgalan's father, Baatar Banzragch, is an engineer and I, Naran Erdene, am an economist.

My son was a clever and cheerful boy and was loved by everyone since his early days. When Amgalan was one year old, he was able to talk with others. He was also able to memorize poems after one or two readings when he was in kindergarten. His memory was amazing. He was really a genius.

But one day I came to realise that my son was seriously ill. In July 2015 when he was five years old, Amgalan started vomiting. In August 2015, he had an MRI scan. When I heard the news of his diagnosis - grade 2 ependymoma - I cried a lot with his dad.

Amgalan went through surgery to remove the tumor in Mongolia. The brain tumor in the bottom of the 4th ventricle, was entirely removed. During the operation, Amgalan's tongue nerves were damaged and he lost his ability to speak and eat. He lost weight, going from 30 kg to 14 kg. He became malnourished.

At the same time, he also got pneumonia and was unable to breathe. He used a pulmotor (a respiratory apparatus for pumping oxygen or air into and out of the lungs) for eleven days. His grandparents and those who loved him were spending nights in a hospital chair. They prayed for every hour and every minute. It was very hard.

After that, we came to Japan and my son received proton beam therapy for 28 sessions. The face of my son became lively and he was able to speak little by little from day to day. His weight returned to normal and I was so happy because I felt that he was healed. At that time, I did not think my son would get sick again. When he had an MRI in January and August of 2016, the scans showed that there was no cancer.

However, in November 2016, he suddenly had backache. His brain cancer had spread to his neck and back. There was also a recurrence of cancer in his head. At that time, I felt really hopeless. My husband and I cried a lot. I was not able to control my tears. Trying not to show my tears to my son, I wept in hiding places.

The most painful thing for people who have cancer is the moment when they are told that the cancer has returned. Doctors discussed his case and decided to do radiotherapy on his back. During this period, the two tumors in his brain were enlarged. New cancer also occurred and started spreading. Thus, it was impossible to have another brain surgery.

When the doctor told me that my son had only six months to live and suggested that we go back to Mongolia, it was very difficult for me. I was cursing myself and said I should have become sick instead of my son. We did not want to give up. We sent documents about my son's illness to several hospitals in Japan and studied the situation in Korea, Germany, and the United States.

We were in pain not knowing what to do. However, one good woman, named Laureline Gatellier, who is living in Japan and also suffering from a brain tumor, introduced us to a university hospital in Tokyo. There, my son had further treatment in the way of chemotherapy. My son was a very smart boy. I am so proud of my son for how he coped with his cancer with so much hardiness and patience even though he was so small. ➤

Above and below: children at a Mongolian orphanage who were presented with gifts from Amgalan's family in his memory. (At the request of the orphanage, the faces of the children have been pixilated to preserve their privacy.)

We are very thankful for those who helped us to receive treatment in Japan and gave us hope.

Postscript by Laureline Gatellier, a friend of Naran

Naran Erdene wrote the above story about her beloved son Amgalan on January 1st, 2018. A few days after that, young Amgalan, aged eight, passed away in his host country, Japan, due to a very aggressive recurrence of his brain tumour which attacked his brain stem, and made it impossible for him to eat, drink or, ultimately, breathe. During the three weeks in which his condition dramatically deteriorated, his parents and their friends did as much as they could, contacting other physicians in Japan and abroad (including the Collaborative Ependymoma Research Network, CERN) all of whom were very supportive.

Shortly after Amgalan's death, the topic of autopsy for future research was raised with the family. Unfortunately, as a post-mortem autopsy would not be beneficial to the family (it would not provide additional information about the circumstances of his death) or to brain tumour future research (the outcome of the autopsy would not be shared in a registry), the family decided against proceeding with the autopsy.

This painful adventure of a little Mongolian boy and his family is heart breaking. The parents sold their house in Mongolia and left their home country so their beloved son Amgalan could be treated and have a better chance of survival. They made the courageous decision to start this new, scary adventure to move to Japan - a foreign country with a different culture, language and social system as well as much higher costs of living, to save the life of their little boy.

Naran obtained a student visa and studied Japanese so hard. Amgalan's father had to work part time, including midnight shifts, though he was the president of his own company in Mongolia. At each step of their journey, until the very end and after, life was incredibly tough. Some funds were raised by wellwishers, to help with the cost of Amgalan's treatment.

As a result of their tragedy, the family are considering the possibility of creating a non-profit brain tumor organisation called "Amgalan" to help children diagnosed with brain tumours in Mongolia. In this way, they will not only be able to turn their tragedy into something positive which helps other children but also it will help to keep Amgalan's soul alive.

Amgalan's funeral in Japan was attended by many, including Amgalan's school friends and his parents' friends and colleagues, reflecting the deep ties the family forged during their time in Japan. A portion of Amgalan's remains was placed in a temple in Japan. His family has now returned home, to Mongolia.

The tough nightmare they endured is now turning now into an amazingly beautiful reality. Only a week after their return to Mongolia, Amgalan's parents expressed their appreciation to their supporters, as their natural way to keep their son alive through their own spontaneous generous actions. Banzragch and Naran visited the hospital where Amgalan had undergone surgery in 2015 in the Mongolian capital Ulan Bator. There they gave presents to the children currently being treated there. They also visited an orphanage, bringing gifts to over 70 unfortunate children.

Amgalan's soul is definitely still alive. Many other children in Mongolia are already positively impacted by his short but love-filled life. ■

Amgalan's Photo Album

Amgalan (front centre) with his family

Mother and son

Amgalan and his family were able to enjoy some simple pleasures during happy holidays in Mongolia

Amgalan

Amgalan and his family join Laureline Gatellier and her family for a meal in Japan

A face full of hope…

Amgalan and his family off on an adventure

A drawing by Amgalan while he was being treated for his brain tumour

All aboard GLIOTRAIN

GLIOTRAIN, an EU funded Marie Sklodowska Curie Innovative Training Newtwork (ITN) award coordinated by the Royal College of Surgeons in Ireland, is a major research study that aims to train the next generation of brain cancer researchers. The project has received funding of almost €3.9 million from the European Commission's Horizon 2020 Research and Innovation Framework Programme and commenced in September 2017.

The project is led by Professor Annette Byrne, Associate Professor, Royal College of Surgeons in Ireland (RCSI) Department of Physiology and Medical Physics and RCSI Centre for Systems Medicine.

Professor Byrne said: "New treatment options for glioblastoma (GBM) patients and effective precision medicine therapies are urgently required. The overall research objective of GLIOTRAIN is to identify novel therapeutic strategies, while implementing state of the art genomics and systems medicine approaches to unravel disease resistance mechanisms."

The consortium brings together leading European and international academics, clinicians, private sector and not-for-profit partners across GBM fields and will address currently unmet translational research and clinical needs in the GBM field by interrogating new therapeutic strategies and improving the understanding of disease resistance.

GLIOTRAIN includes major academic and industry researchers from the United States (Champions Oncology) and across Europe, including collaborators in Ireland (Cancer Trials Ireland); Germany (University of Stuttgart, GeneXplain, Insilico Biotechnology, Yumab); Luxembourg (Luxembourg Institute of Health, University of Luxembourg, ITTM S.A.); Belgium (VIB, University of Leuven, Oncurious, Agilent Technologies); France (ICM Brain and Spinal Institute Paris, CarThera); Netherlands (Erasmus Medical Centre, Teva Pharmaceuticals, Mimetas, Pepscope) and the UK (International Brain Tumour Alliance). The project will also be supported by the Irish Brain Tumour Biobank which was established at Beaumont Hospital Dublin National Centre for Neurosurgery, through generous funding from Brain Tumour Ireland (https://braintumourireland.com).

Above: The Early Stage Researchers (ESRs) who are working with the GLIOTRAIN initiative are (left to right): Gonca Dilcan Durdağ (Turkey), Linqian Weng (China), Federica Fabro (Italy), Ioannis Ntafoulis (Greece), Viktorija Juric (Croatia), Francesca Lodi (Italy), Manasa Kalya Purushothama (India), Romain Tching Chi Yen (French Polynesia), Yahaya Abubakar Yabo (Nigeria), Mohammed Ahmed (Palestine), Kieron White (Wales), Chiara Boccellato (Italy), Nivetha Krishnamoorthy (India), Ayoub Lasri (Spain)

The Research Project

Worldwide, there are an estimated 240,000 cases of primary malignant brain and nervous system tumours per year. GBM is the most frequent, aggressive and lethal of these[1]. The disease belongs to a group of invasive brain tumours derived from glial cells. Glial cells surround neurons and provide support for and insulation between them. GBMs have an extremely poor prognosis despite aggressive treatment (surgical resection where possible and adjuvant radio-chemotherapy with temozolomide). Despite significant efforts over forty years, clinicians are as yet unable to offer GBM patients a curative therapy. Thus new treatment options including effective precision medicine therapies are urgently required. This can only be achieved by focused multi-sectoral industry-academia collaborations in newly emerging, innovative research disciplines. The research objective of GLIOTRAIN is to identify novel therapeutic strategies for treating GBM patients, while implementing state of the art next generation sequencing, systems medicine and integrative multi-omics (see Information Box for descriptions) to unravel disease resistance mechanisms.

Diverse elements underpin the complexity of GBM. These elements include:

(1) the diffuse and infiltrative nature of the tumour limiting the ability of surgeons to remove the whole tumour
(2) the rapid rate at which GBM cells divide and multiply
(3) the appearance of treatment resistance
(4) the blood brain barrier (BBB) preventing access of drugs to the brain
(5) the activation of specific gene mutations within the tumour
(6) the presence of many different types of cell within the tumour itself

The research projects within GLIOTRAIN will be grouped into two major work packages. The first work package (WP) is called GLIOTREAT, and will focus on predicting new treatment strategies. New delivery methods, for example using ultrasound to open the BBB to allow drugs

Above: Professor Annette Byrne, Royal College of Surgeons in Ireland (RCSI) Department of Physiology and Medical Physics & RCSI Centre for Systems Medicine. Professor Byrne is leading the GLIOTRAIN consortium.

into the tumour, or the repackaging of drugs to enable delivery across the BBB, will be investigated in this WP. The use of immunotherapies for treatment of GBM will also be explored. Immunotherapies are a type of cancer treatment that boost the body's natural defences to fight the cancer. Immunotherapies use substances made by the body or in a laboratory to improve or restore immune system function. The systems medicine and 'omic approaches will be used to predict the best type of drug to treat different subtypes of GBM. There are four subtypes of GBM that are all likely to respond differently to different therapies.

The second WP is called GLIORESIST. In this WP the mechanisms that lead to resistance of GBM to treatment will be investigated. Computer models and multi-'omics will be employed. Results from all of the technologies employed in the project will be integrated together to give a "landscape" of GBM resistance.

Student Training

GLIOTRAIN will exploit the complexity of GBM to address European applied biomedical research training needs. Fifteen innovative, creative and entrepreneurial early stage researchers (ESRs) will be trained over the course of the project. There is a current need in academia and the private sector for researchers who have been trained in an environment that spans different research areas (often scientists only receive training in one very small niche) and who can navigate confidently between clinical, academic and private sector environments to progress applied research findings towards improved patient outcomes.

Each researcher will be registered on a PhD programme and will undertake their own research project under the supervision of experienced principal investigators. In addition, students will all take part in the GLIOTRAIN Network-wide training programme. This programme has been designed to give students exposure to different research disciplines and to both academic and industry environments.

Training events include systems medicine and multi-'omics workshops, a Commercialisation Bootcamp and events to improve the ESRs' communication skills.

We are excited to begin work and are delighted to have Kathy Oliver from the IBTA on the External Advisory Board for GLIOTRAIN. We will be working closely with the IBTA over the coming three years and will be sharing news, events and updates over the course of the project. Moreover, we were pleased that our first Network-wide event was held in April 2018, and included a mini-symposium led by Kathy, where GLIOTRAIN students had the opportunity to consider the "bigger picture" impact of their research and how GLIOTRAIN findings may ultimately affect and improve patient outcome.

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie grant agreement No 766069. ■

Definitions

1.Next Generation Sequencing (NGS)
DNA sequencing is the process of determining the sequence of nucleotide bases (As, Ts, Cs, and Gs) in a piece of DNA. NGS techniques are new, large-scale approaches that increase the speed and reduce the cost of DNA sequencing. With the right equipment and materials, sequencing a short piece of DNA is relatively straightforward. It requires breaking the DNA into many smaller pieces, sequencing the pieces, and then reassembling the sequences. Thanks to new methods that have been developed over the past two decades, genome sequencing is now much faster and less expensive than it used to be. In cancer, NGS can help to personalise medicine – it can inform researchers about the differences in DNA between GBM tumours and normal brain tissue which can indicate new targets for therapy and it can even show differences in different groups of patients.

2. Multi-'omics
Multi-'omics is a biological analyses approach where the data sets are multiple "omes". It incorporates information about the genome (DNA) and the proteome (the proteins being produced by the body) amongst others. Normal tissue can be compared to GBM tumour tissue to highlight differences and help guide researchers in the design of more targeted drugs.

3. Systems Medicine
Systems medicine involves computational, statistical, mathematical analysis and modelling of disease mechanisms, disease progression and remission, disease spread and cure, treatment responses and adverse events as well as disease prevention both at the population and individual patient level. Systems medicine (https://www.casym.eu/what-is-systems-medicine/) thus aims to improve patient outcomes. In this project, known biological information (from NGS and multi-'omics) of GBM tumours will be fed into computer models that can then simulate what happens in the human body. The models are refined regularly when new biological data is available. The effect of anti-cancer drugs, whose mechanism of action is known, can be introduced into the computer system which can predict the effect on the GBM tumour. This is then tested experimentally and the results fed back into the computer to refine predictions. The simulations can inform researchers on the best drugs to treat different GBM patients having different genetic signatures. ■

[1]Crocetti E et al, Eur J Cancer. 2012 Jul;48(10):1532-42. doi: 10.1016/j.ejca.2011.12.013. Epub 2012 Jan 7.

SNO Society for NeuroOncology

IBTA International Brain Tumour Alliance

Zimbabwe Brain Tumour Association

Excerpts from the Report of the first Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting

working together…improving outcomes…sustaining hope
for adult and pediatric brain tumour patients in
central, south, east and west Africa

18th - 20th October 2017

The Tower Hotel, London, United Kingdom

We are pleased to include in this edition of Brain Tumour magazine excerpts from the 2017 S-SANOC meeting. The full report is available here in digital format:
https://issuu.com/ibta-org/docs/ibta_ssanoc-report_final_20mar2018
For a hard copy of the report, please contact kathy@theibta.org

Acknowledgements and Sponsors

The Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting was held in association with:

in association with Mark Bernstein, Greg Wilkins-Barrick Chair in International Surgery, University Health Network, University of Toronto, Canada

With appreciation to the organizing committee for the S-SANOC meeting:

Kathy Oliver (United Kingdom), **Christine Mungoshi** (Zimbabwe), **Gordon Oliver** (United Kingdom) **Mark Bernstein** (Canada), **Gelareh Zadeh** (Canada), **Linda Greer** (United States), **Chas Haynes** (United States), **Jason Huse** (United States), **Ken Aldape** (Canada)

With sincere thanks to the following individuals and companies for their much appreciated support of the S-SANOC meeting:

Mark Bernstein, Greg Wilkins-Barrick Chair in International Surgery, University Health Network, University of Toronto, Canada

The SNO Foundation and Chas Haynes, Executive Director, Society for Neuro-Oncology, United States

In addition…

Grateful thanks go to **Ms Christine Quah, Manager, Global Accounts, HelmsBriscoe** (www.helmsbriscoe.com) for her invaluable help in finding and securing our S-SANOC venue.

Many thanks also to **The Tower Hotel**, for their help with our accommodation and conference arrangements.

The Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) Planning Meeting, a project of the International Brain Tumour Alliance (IBTA) in association with the Society for Neuro-Oncology (SNO) and the Zimbabwe Brain Tumour Association (ZBTA), was a wholly independent activity and was conceived, planned and carried out by the IBTA, SNO and ZBTA. The content of the S-SANOC meeting was not based on any specific treatment or therapy and full content and editorial control remained with the organisers. For details of the IBTA's sponsorship and transparency policies, please see www.theibta.org

Executive Summary

THE 2017 Sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting brought together a range of stakeholders focussing on the care and support of people with brain tumours and their families living south of the Sahara on the African continent.

Sub-Saharan Africa comprises the largest land area of the continent with those countries north of the Sahara making up North Africa and part of the League of Arab States. Sub-Saharan Africa consists of 46 countries. In 2016, the population was more than 995 million. Over 1,000 languages are spoken across sub-Saharan Africa.

National health systems and healthcare spending vary widely from country to country. Communicable diseases such as HIV/AIDS, lower respiratory tract infections, diarrhoeal diseases and malaria are among the top four killers in sub-Saharan Africa and generally command the main focus of attention in healthcare.

Recently, however, there has been an enhanced focus on non-communicable diseases due to the increasing incidence of such illnesses as stroke, asthma, diabetes, coronary heart disease, chronic hepatic and renal diseases, and cancer.

Amidst the many substantial challenges facing people in sub-Saharan Africa, brain tumours are low on the ladder of healthcare priorities. Additionally, brain tumours are rare and country-specific hospital and population-based registries, if they exist at all, are incomplete. So the accurate incidence and prevalence of brain tumours is largely unknown.

There is good news

But the good news for the sub-Saharan Africa brain tumour community is the emerging new focus of attention on it which is being led by highly dedicated and pioneering healthcare professionals with a determined and long-term commitment to improve the situation for people whose lives have been touched by this devastating disease.

The first-ever S-SANOC planning meeting was a coming together of some of these health professionals, along with brain tumour patient advocates, neuro-oncology nurses, members of neuro-oncology learned societies and other healthcare professionals with the aim of discussing the challenges and potential solutions for caring for people with brain tumours in sub-Saharan Africa.

On 18th and 19th October 2017, the IBTA was delighted to welcome 33 participants from 16 countries to the S-SANOC meeting in London, UK. The S-SANOC meeting was run in conjunction with the Zimbabwe Brain Tumour Association (ZBTA), the Society for Neuro-Oncology (SNO), Dr Mark Bernstein (the Greg Wilkins-Barrick Chair in International Surgery, University of Toronto, Canada) and the SNO Wilkins-Barrick Course in Neuro-Oncology.

The SNO Wilkins-Barrick Course in Neuro-Oncology was established in 2015 and provides seed funding for neuro-oncology symposia or courses in the developing world. As part of the 2017 round of funding, a specific call for applications from sub-Saharan Africa was made by SNO. During the period of the grant application process, SNO also became aware of the efforts of the IBTA and ZBTA in connection with brain tumour patients and advocacy communities in sub-Saharan Africa and the two organisations' desire to improve outcomes for brain tumor patients and their families in this part of the world.

Recognizing the congruent interests of SNO and the IBTA and ZBTA a decision was made to invite the SNO Wilkins-Barrick applicants and African patient advocates to London to examine the challenges and potential solutions for improving the care of brain tumor patients in sub-Saharan Africa. In addition, brain tumor patient advocates from Zimbabwe, Cameroon, South Africa and Uganda were given the opportunity to present their perspectives on the current situations for brain tumor patients in their countries.

The IBTA also presented on its current work in the international advocacy and awareness-raising field. In addition, representatives of the following neuro-oncology societies were present at the S-SANOC meeting: the European Association of Neuro-Oncology (EANO), the Indian Society of Neuro-Oncology (ISNO), and the Asian Society of Neuro-Oncology (ASNO). It was further hoped that bringing together key stakeholders from the region would be conducive to the development of a multi-stakeholder African neuro-oncology society that would take a leadership role in coordinating efforts to improve brain tumour patient care.

The challenges

Over the course of the S-SANOC meeting, the following challenges were identified (however, this list is not exhaustive):

- late and/or incorrect diagnosis or no diagnosis
- insufficient access to medical care on all levels from primary through to tertiary
- an acute shortage of healthcare professionals specializing in neuro-oncology
- a critical shortage of up-to-date and well-functioning medical equipment such as radiotherapy machines
- lack of specialist pathological expertise (especially in the increasingly-important arena of molecular profiling)
- systemic weaknesses, eg lack of funding for supporting staff development and educational training, procurement of equipment and facilities; weak management practices; lack of national and pan-sub-Saharan Africa guidelines for the treatment and care of brain tumour patients
- very few not-for-profit brain tumour patient and caregiver support, information and advocacy organisations. Those which already exist struggle significantly to provide much-needed services and fill gaps in support and information provision.
- the practice of traditional medicine as the main source of treatment and advice for a large number of patients
- substantial stigma attached to brain tumours and their symptoms, for example epilepsy, which is perceived by some as "being cursed", "being possessed", "being punished for a previous wrong committed", etc.
- absence of a pan-sub-Saharan Africa neuro-oncology society
- the need for comprehensive palliative/supportive care and end-of-life care for brain tumour patients
- the necessity for all parts of sub-Saharan Africa (east, west, south and central) to collaborate, network and communicate with each other better

Recommendations

In response to the challenges above the following recommendations were made at the S-SANOC meeting:

1. To organize a neuro-oncology educational course/conference for 2018 in sub-Saharan Africa, to be jointly funded by:

- the Society for Neuro-Oncology (SNO) Wilkins-Barrick International Outreach Course Grant in Neuro-Oncology
- the European Association of Neuro-Oncology (EANO)
- the International Brain Tumour Alliance (IBTA)
- other fundraising efforts

This course/conference - which would either be held as part of an already-existing international meeting planned for 2018 or as a stand-alone event - could address some of the challenges listed above and specifically disseminate the latest information on brain tumour treatments and care.

2. To establish a multi-stakeholder sub-Saharan Africa neuro-oncology society. For this, involvement of stakeholders in the region should broadly reflect the cultural and other needs of the brain tumour population within sub-Saharan Africa. Such a society could - provided it functions on a sustainable and relevant basis – help address the challenges listed above and help overcome some of the barriers which negatively affect outcomes for people with brain tumours in sub-Saharan Africa.

3. To involve brain tumour patient advocacy organisations in both the proposed 2018 and any future annual educational courses/conferences and also involve them in the proposed sub-Saharan Africa neuro-oncology society. Involvement of patient advocates in all aspects of the brain tumour journey is crucial in order that the patient and caregiver perspective is provided throughout.

Presentation 1

Dar es Salaam, Tanzania Group 1: Dr Thierry Muanza and Dr Ekokobe Fonkem

Above: Dr Thierry Muanza (right) and Dr Ekokobe Fonkem (left) gave a joint presentation on their proposal for a neuro-oncology course in Tanzania

Dr Thierry Muanza is a radiation oncologist and clinical trials and translational researcher. He is a member of the Board of Directors for Brain Tumor Foundation of Canada, and Assistant Professor to the Department of Oncology and an Associate Member of the Departments of Experimental Medicine and Neurology & Neurosurgery of the Faculty of Medicine at McGill University, Canada. He also has experience working and training at various locations across North America.

Dr Ekokobe Fonkem, a neurosurgeon originally from Cameroon, West Africa, is the Director of Baylor Scott and White Health System Neuro-Oncology Program in Texas, USA and an Associate Professor of Surgery at the Texas A&M University Health Science Center. He is involved in basic, translational and clinical research on both primary and metastatic brain tumours as well as their neurological complications.

Drs Muanza and Fonkem highlighted the following challenges in sub-Saharan Africa:

Some of the challenges

- There needs to be a transfer of knowledge among professionals. The approach to brain tumour treatment is evolving from being based on a tumour's grade and type (its appearance under the microscope) toward analysis of its molecular and genetic features.
- Education needs to address local cultures, each of which has its own societal and belief system. Patient advocacy groups would be key.
- The importance of cultural beliefs in African society should not be underestimated.
- Cancer is increasingly becoming a major economic and social burden in this part of the world due in part to better living standards and a longer lifespan.
- There is an increased incidence and prevalence of primary high-grade gliomas and meningiomas alongside increasing rates of secondary brain tumours that have spread from other cancers, such as lung, breast, cervical and prostate.
- The healthcare approach is not adequate in sub-Saharan Africa and there is a general lack of appropriate neuro-oncology education and training across the region, a lack of government support and poor public awareness of brain tumours.
- The on-going challenge for a sub-Saharan Africa neuro-oncology society will be to try and address the lack of professionals and limited resources.
- There is also a pressing need to develop a brain tumour registry to assess the impact of brain tumours and the resources that are needed. How do we know what is needed unless we know what it is like on the ground?

Some potential solutions

- Bridge the divide between patients, caregivers, medical professionals and traditional healers in neuro-oncology.
- Link local/domestic specialists with professionals from the developed world.
- Implement modern technology.
- Adapt to the local environment.
- Accommodate cultural beliefs, especially the widespread reliance on traditional healers.

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- Create/increase awareness of brain tumours in sub-Saharan Africa.
- Provide an opportunity for multi-stakeholder collaboration between physicians and patients in sub-Saharan Africa.
- Address a variety of important topics, which include common brain tumours, management, the potential role of telemedicine, and other advances.
- Consider the role of cultural beliefs.
- Establish brain tumour registries.
- Assess quality of life for patients and their families.
- Analyse the role that patient advocacy plays, and evaluate brain tumour care and outcome in Africa.

Presentation 2

Dr Daniel Fulkerson, representing a clinical group in Eldoret, Kenya

Above: neurosurgeon Dr Daniel Fulkerson (standing) has worked in Eldoret, Kenya and has an intimate knowledge of the challenges there in treating pediatric brain tumour patients.

Dr Daniel Fulkerson is Associate Professor of Neurological Surgery at Indiana University School of Medicine, USA and performs both adult and paediatric neurosurgery for Goodman Campbell Brain and Spine, Indianapolis, USA. He also cares for patients at Riley Hospital for Children, Peyton Manning Children's Hospital at St Vincent's and Methodist Hospital. He primarily cares for children with brain tumours, hydrocephalus, spine disorders and spina bifida. He specializes in minimally-invasive surgery of the brain and spine, including endoscopic treatment of brain tumours and hydrocephalus.

Eldoret, Kenya (where Dr Fulkerson has links) literally means "stony river" and is a city in the Rift Valley Province with a population of around 200,000 people (rising to around 800,000 including the surrounding lands). The large catchment area means that the city's hospital is very busy. With 800 beds, Moi Teaching and Referral Hospital treats approximately 8,000 oncology patients each year. However, as Eldoret is situated at an elevation of 7,000 to 9,000 feet (2,100 to 2,700m), the area has very limited access. The hospital was first opened in 1917 as a cottage hospital, but became a referral hospital with the establishment of Moi University in 1984.

Moi University School of Medicine was established in 1988, as Kenya's second medical school and its first students graduated in 1997. Indiana University Medical School (USA) where Dr Fulkerson works, has nurtured an important relationship with Moi University and its medical students and its medical staff regularly visit Moi Hospital (over 500 Indiana University students having visited so far). Moi Teaching and Referral Hospital is the only hospital in the northern half of the country with neurosurgical capabilities.

Dr Fulkerson has built up a relationship with the institution and developed many friendships with the staff.

Through multiple trips to provide neurosurgical care, he has gained an intimate working knowledge of the capabilities and needs of Moi Hospital.

Above: Skills transfer is crucial for physicians in Kenya, said Dr Fulkerson

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Dr Fulkerson explained that skills transfer is crucial for the physicians in Kenya. For example, it is not routine to give brain tumour patients any prevention for deep vein blood clots after surgery. To implement simple preventative practices will have tremendous benefit for improving outcomes.

Through his work in the country Dr Fulkerson had been able to successfully bring technologies and methods to medical professionals in Eldoret, demonstrating that good progress is achievable.

Solutions for complex problems

He stressed that many of the patients' conditions are not simple cases and are extremely challenging surgeries even in the most advanced operating suites. He told about one patient who survived major surgery but died two days later from a pulmonary embolism, which may have been preventable through what would be considered basic care in developed countries.

Photographs in his presentation of the operating suite and available equipment showed that Moi Hospital had only very limited anaesthesia, and ageing technology.

"They need sustainable technology and skills transfer. Implementing what is the standard of care in the USA is not possible with technology there," he said.

An alternative to advanced technology is to use ultrasound as an additional aid to surgery. Dr Fulkerson showed a short video of an ultrasound machine being used to identify and locate a brain tumour. He explained that such relatively inexpensive technology can be used to locate a small target. However, accomplishing this requires knowledge, training, and tuition in troubleshooting and obtaining pictures.

Moi Teaching and Referral Hospital has the capability to become a training centre for paediatric neurosurgery and a teaching hub for the wider area.

Future ideas include using telemedicine, offering material support, research, and helping orchestrate public health initiatives such as road safety programmes.

Head injuries from road traffic accidents are remarkably common in Kenya and a public health initiative that increased helmet use will have a dramatic effect on improving brain tumour care. This is because fewer head injuries requiring surgery would mean less strain on the neurosurgical department, potentially freeing-up resources for brain tumour surgery.

Presentation 3

Dar es Salaam, Tanzania Group 2: Dr Trish Scanlan

Dr Trish Scanlan is an Irish paediatric oncologist who has lived and worked in Tanzania since 2006. Alongside her local colleagues and the non-governmental organization (NGO) Tumaini la Maisha (Their Lives Matter) which she founded, she has helped create the national pediatric oncology service in Tanzania. Care is offered free of charge to all children and is now available at three centres across the country. Dr Scanlan hopes to add more centres to the network until every child with cancer in Tanzania has a chance of cure.

Above: Dr Scanlan and her team have endeavoured to adopt international protocols and standards of care for children with cancer, including brain tumours, in Tanzania.

Sharing some of her own personal story of twice being diagnosed with breast cancer, Dr Scanlan spoke of how Dar-es-Salaam captured her heart during a visit in 2006, prompting her to join the paediatric oncology team at The Ocean Road Cancer Institute (ORCI) the following year.

Tumaini la Maisha's vision is that all children with cancer in Tanzania will have easy, free access to locally-based, high-quality, curative and palliative cancer treatment, leading to survival outcomes similar to resource-rich settings. The plan is to reach every child with cancer in Tanzania in five years. Displaying a graph showing how lifespan is closely related to the wealth of the country, she quoted the words of the late statistician and public speaker Dr Hans Rosling:

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"There's really no reason why everyone can't move to the richer healthier corner of the graph."

"There was a huge step forward in paediatric cancer care in Tanzania in 2004, when the government removed a lot of barriers to medical care which began to be offered at no cost, although the lack of resources meant that the cupboards were probably often bare," Dr Scanlan said.

In 2005, childhood cancer had a survival rate of under 10% in Tanzania.

"One young Tanzanian girl who had terminal cancer and was left to die in the night without any pain medication or intravenous fluids had a profound effect on me," she said. "This represented everything that was needed.

Above: Dr Trish Scanlan: "Ependymoma is the most common type of pediatric brain tumour seen in Tanzania, although a wide variety of brain tumours are diagnosed, ranging from craniopharyngioma to germ-cell tumours to DNETs (dysembryoplastic neuroepithelial tumours)."

Achieving positive change

"When I first arrived at Ocean Road Cancer Institute in Dar-es-Salaam, it was the only cancer care facility in the country, which has a population of 40 million half of whom are children.

"Paediatric patients were left alone for hours on the cancer ward, unsupervised and untreated because there was insufficient money to pay nurses to work night shifts. On the night the young girl died, in that moment I resolved that change absolutely had to happen. But how?"

Dr Scanlan has five thoughts as to how to achieve positive change:

1. **Start with what is essential.**
2. **Prove that your efforts are having an effect.**
3. **Build up slowly as the service grows.**
4. **Give teaching from the very first day.**
5. **Engage with others both locally and internationally**

Dr Scanlan added that cost is an invisible border to care and so they have maintained the principle of free care. "Palliative care also needs to be considered as an essential in Tanzania," she said.

Since Dr Scanlan started working to improve cancer care in Tanzania, children are now seen regularly by healthcare professionals, rather than being abandoned.

"When I first arrived, rudimentary oncology management - which is taken for granted in wealthy nations - was not being performed in Tanzania either," Dr Scanlan said. "We have ensured that children receive basic tumour staging using the imaging technology (e.g. X-rays) to which they have access. We have also adopted international protocols and standards of care."

In sub-Saharan African countries, it is essential that doctors provide accurate diagnosis information for children with suspected cancer. To overcome the lack of expertise and equipment in Tanzania, Dr Scanlan's centre twinned with Our Lady's Children's Hospital in Dublin, Ireland. This allows Tanzanian doctors to send tissue sample packages to Ireland every week for a complete molecular analysis.

Dr Scanlan's team has received funding to give training that will establish a pathology service in Dar-es-Salaam, and this is intended to also serve the rest of the country.

Tumaini La Maisha – notable achievements

Through a series of touching photographs, Dr Scanlan highlighted some of the many achievements that Tumaini La Maisha has accomplished for improving paediatric cancer care, including that for brain tumours, in Tanzania.

Dr Scanlan said: "When I arrived there was no oxygen and the only laboratory services were in a shed which closed at 3pm. Now, children with cancer have access to free CT and MRI scanning equipment and there are no delays in accessing radiation therapy although presently there is only one cobalt radiation machine available. Children are now given psychosocial support, which includes playtime, compassionate care, fun activities, outings and good nutrition including 'magic porridge'. Care packs, which contain many basic essentials, are given to families and a skills room is available for parents."

Dr Scanlan also described the 'Child Life Programme', which educates children about medical procedures with the use of dolls to show what will happen to them and which helps remove some of their apprehensions.

Photos by MVF Studios

Education is important and it has therefore been one of the key activities at Tumaini La Maisha. They have access to 35 experts from around the world, and are training people locally.

They have helped establish an MSc course in paediatric oncology, which has already led to two homegrown graduates. Prior to this, there were no Tanzanian-trained paediatric oncologists in the country. The aim is to help train sufficient paediatric haematologists/oncologists for Tanzania and East Africa.

Additionally, Tumaini La Maisha has developed - in collaboration with MUHAS (Muhimbili University of Health and Allied Sciences) and the Tanzanian government – a Certificate Programme for Nursing in Paediatric Oncology and Haematology. They hope to run the course twice in 2018.

Through a community education programme, Tumaini La Maisha has been using local and national media platforms to deliver easy-to-understand messages to the general public about children's cancer, which includes early warning signs and how to access care. Importantly, they are not working in isolation but are working in collaboration with others, including traditional healers, to build relationships so that their message effectively reaches as wide an audience as possible.

Dr Scanlan said: "I believe it's important to continually review progress and ask 'Has this made any difference?' Prior to our interventions, a single ward bed would sleep three children, each of whom would have been receiving different therapies and treatments. Now, it is one child per bed despite the fact that the number of children coming to the hospital has increased dramatically in the time we have been in operation in Tanzania. In 2005, fewer than 150 children were receiving treatment for cancer and in 2016 approximately 600 children were treated."

Dr Scanlan said that outcomes have also improved. She showed a chart which listed rates of 'complete remission'/'on treatment' and that they had increased from approximately 42% in 2013 to nearly 50% in 2015. Citing a case study of a boy with a large Wilms' tumour (a type of kidney cancer), she said that in sub-Saharan Africa there is a wide variety of cancers and tumours, many of which are seen only when the disease is extensive. Thus, they present a complex medical and surgical challenge.

"When I arrived in Tanzania," Dr Scanlan said. "I found that, amazingly, the statistics showed that in 2005 there were no children with brain tumours seen at the hospital. I met with the team at the hospital and suggested that this fact should be publicised as it appeared that Tanzania was free of the problem of paediatric brain tumours! In reality, we all agreed that the problem did exist and it was quite literally that no children with paediatric brain tumours were being sent to the paediatric oncology centre."

The work continues

Now Dr Scanlan has a significant number of paediatric brain tumour patients. In 2015, 10.9% of conditions seen in the centre were brain tumours. Thanks to the partnership with the hospital in Dublin, they have access to accurate molecular information about these neoplasms. Ependymoma is the most common type of brain tumour seen although brain tumours of a wide variety are diagnosed, ranging from craniopharyngioma to germ cell tumours to DNETs (dysembryoplastic neuroepithelial tumours).

Dr Scanlan added: "Our charity's vision is to pool resources to create a hub- and-spoke paediatric cancer network in Tanzania. With Muhimbili National Hospital at the centre generating protocols and providing education in an open-source manner, the network would be a four-tier system of primary, secondary, tertiary and quaternary care. Primary and secondary centres across the country would act as spokes by provisionally diagnosing, stabilising and treating patients before transferring them to the tertiary hub."

Dr Scanlan showed a map of the proposed cancer network in Tanzania: "No one would be more than one day's journey from a centre, and each centre would know what to do."

A mobile money transfer system would be implemented, whereby individuals can be sent travel money directly via their mobile phone. In early 2016, Tanzania became the first country in the world to achieve full interoperability of mobile money services, allowing users of different mobile money services to transact directly with each other. Forty-three per cent of adults in Tanzania are already using these services to pay bills, make transfers to family and friends and conduct business transactions.

Dr Scanlan also asked the S-SANOC participants to consider joining the 'T. Pot' (Tanzanian Paediatric Oncology Team), which is an international collaboration of organisations and universities supporting the goals of Their Lives Matter.

She insists that care must remain completely free for all children with cancer so Muhimbili National Hospital

and Their Lives Matter presently share all costs, which amounts to just €320,000 (US$377,000) per annum.

With this sum, they treat more than 500 children. Put into context, that amount would cover the costs of care for just three children with childhood leukaemia in Europe.

"There is so much we want to do," said Dr Scanlan. "Brain tumours have lagged behind and we want to bring together neuro-oncologists, surgeons, and other relevant professionals to develop training and research facilities, and then offer it across the region."

Presentation 4

Professor Alan Davidson, Cape Town, South Africa

Above: Prof Alan Davidson is head of the Paediatric Haematology-Oncology Service at the Red Cross War Memorial Children's Hospital in Cape Town, South Africa.

Professor Alan Davidson is head of the Paediatric Haematology-Oncology Service at the Red Cross War Memorial Children's Hospital in Cape Town, South Africa and the past chair of the South African Children's Cancer Study Group. He is the former chair of the local organizing committee for the SIOP (International Society of Paediatric Oncology) Cape Town conference in 2015. He also served as co-chair of SIOP's PODC Adapted Treatment Regimen Working Group which commissions and guides the publication of adapted treatment guidelines. His clinical and research interests include paediatric brain tumours, B-cell malignancy and other HIV-related cancers in children, genetic syndromes predisposing to childhood cancer, stem cell transplantation for primary immunodeficiency and adapted therapy regimens for low and middle income settings.

He has co-chaired South Africa's annual Paediatric Brain Tumour Workshop since 2008, and currently serves as co-chair of SIOP's Paediatric Oncology in Developing Countries Committee.

Professor Davidson helps organise and run South Africa's annual Paediatric Brain Tumour Workshop (PBTW), and he has been co-chair of the event since 2008. The PBTW event has established a strong agenda for advancing the cause of paediatric brain tumours in sub-Saharan Africa, thanks to the collaboration of the combined neuro-oncology service of the University of Cape Town and its affiliated teaching hospitals. It is co-hosted by leading experts Professor Anthony Figaji (Head of the Department of Paediatric Neurosurgery) and Professor Jeannette Parkes (Head of the Department of Radiation Oncology).

The PBTW originated as a satellite meeting of the International Society for Paediatric Neurosurgery (ISPN). The target audience is neurosurgeons, paediatric and radiation oncologists and colleagues from related disciplines, such as radiologists and pathologists. Attendees for the PBTW come from all over South Africa and beyond.

"'Beyond' is limited by money," he said. "We have been trying to raise funds to support attendance of colleagues from more sub-Saharan countries. So far, we have had delegates from Angola, Kenya, Malawi, Nigeria, Sudan and Uganda."

Dr Davidson summarized some key features of sub-Saharan Africa and the developing world:

- **Since 2000, global under-five mortality per annum has been declining – from 9.9 million in 2000 to 6.3 million in 2013.**
- **Ninety per cent of those deaths are taking place in low and middle-income countries (LMICs).**
- **Prematurity, intrapartum death, pneumonia, diarrhoea and malaria are some of the most common causes for these deaths.**
- **The fall in mortality rates is partly accounted for by declines in infectious disease deaths.**
- **At least 176,000 children under age 15 are diagnosed with cancer each year.**
- **Eighty per cent of these children live in LMICs.**
- **Cancer mortality is roughly twice as high in LMICs,**

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compared to that of high-income countries.

- **Deaths in these countries account for the majority of the world's 90,000 childhood cancer deaths each year.**

Many childhood brain tumour patients are 'invisible patients' who are undetected in low and middle-income countries. Based on northern hemisphere data, about 20% of childhood cancers are paediatric brain tumours, but numbers in the developing world are quite different. Available data showed that in Ghana, paediatric brain tumours account for just 3.4% of cancers in a tertiary referral centre. In Namibia this figure is 5.2%, and in Nigeria, 6.9% of childhood cancers are recorded as brain tumours.

"These low numbers reflect an under-reporting of these invisible patients. But at least this is changing," said Prof Davidson. "Data from Bangladesh shows that the proportion of childhood cancers recorded as paediatric brain tumours has increased from virtually 0% in 2001 to 4.4% in 2014. These figures are estimates and we won't know the actual figures without registries."

He added: "Money solves problems and lack of resources is perhaps the greatest challenge faced in sub-Saharan African countries."

Other challenges include the:

- **low rate of diagnosis and referral of paediatric brain tumours**
- **general lack of functioning, multi-disciplinary teams**
- **absence of standardised treatment protocols**
- **widespread use of inappropriate therapies which have excessive toxicity**
- **absence of published data**
- **inaccurate media and parental expectations**

"There is also a pressing need to encourage communication between surgeons and other healthcare professionals in these countries," Prof Davidson said. "We must not be left to work in isolation as is often the case now. North-to-south collaboration needs to be encouraged [referring to the richer, northern hemisphere nations]. But this communication must be two-way because wealthier countries in the north have a duty to understand the context of the sub-Saharan region, rather than trying to teach our region how to do things.

"There are challenges and obstacles, such as the expense and great distances of travel in the subcontinent, the variety of settings across sub-Saharan Africa, and the difficulties and costs of translation. Money is the real issue…"

Presentation 5

Dr James Balogun, representing a clinical group in Abuja, Nigeria

Above: consultant neurosurgeon Dr James Balogun represented a clinical team from the Ibadan/Abuja region in Nigeria.

Dr James Balogun is a consultant neurosurgeon at University College Hospital (UCH) in Ibadan and faculty member at the Department of Surgery, College of Medicine, University of Ibadan, Nigeria. He is also a visiting consultant neurosurgeon at the University of Ilorin Teaching Hospital. His focus is on the epidemiology, science and surgery of adult and pediatric brain tumors particularly in Africans. Dr Balogun's clinical practice also includes endonasal endoscopy, pituitary surgery and awake and ambulatory craniotomy. He also anchors the neuro-oncology tumor board in his institution.

Nigeria faces significant challenges in brain tumour care. A country with a population of 193 million, which is expected to double by 2050, Nigeria is a nation of diverse ethnic and religious groups. Most patients have to pay for their care, which is typically at great personal cost. Allocation for health spending varies between 6% and 15% of the national budget.

Typically, there is a big lag-time between a doctor's referral and neurosurgery for brain tumour patients in Nigeria. Hence, improving communication and fostering collaboration is a key priority. There are 'islands of excellence' across sub-Saharan Africa but there is little

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Above: Dr James Balogun: an important goal of the 2018 neuro-oncology course in sub-Saharan Africa would be to identify knowledge gaps and stimulate research

communication between these centres. There is also a need to facilitate multi-disciplinary care/tumour boards in neuro-oncology and to provide an opportunity for the identification and collaboration of the available brain tumour workforce.

"There is minimal brain tumour research in Africa and few facilities for molecular analyses, which is a pivotal diagnostic feature in the latest WHO classification of brain tumours," said Dr Balogun. "Hence it is very important to stimulate research through the identification of knowledge gaps and to improve the understanding of palliative and end-of-life care in brain and spinal cord tumour patients. People do not die in dignity, and there is little support for the dying."

Dr Balogun said that there is a wide variety of pathology expertise across the African continent. For example, Nigeria has 158 trained pathologists while Cameroon has 12, and Somalia has none. Treatment needs to be optimised in line with the resources available.

Dr Balogun's team, which is based at University College Hospital in Ibadan, consists of neurosurgeons, pathologists, radiologists, radiation oncologists, neurologists and paediatric neurologists. They have a collaboration with the Nigerian Academy of Neurosurgeons and Nigerian Societies of Neurological Sciences.

"In relation to a sub-Saharan Africa neuro-oncology society, now is the time to pool resources and pull people together rather than being islands. We should promote education and training in all aspects of neuro-oncology. We can also leverage relationships with organisations, such as SNO (Society for Neuro-Oncology), EANO (European Association of Neuro-Oncology), ASNO (Asian Society for Neuro-Oncology) and ISPNO (International Symposium on Pediatric Neuro-Oncology) and create a platform to engage with the pharmaceutical industry."

There is a lack of neuro-oncology specialists across sub-Saharan Africa, and industry, health organisations and government support tend to be focused on infectious diseases, rather than cancers. Geographical divides and ideological differences are potential barriers, while previously-held inaccurate stereotyped beliefs must be done away with if the future prospects of brain tumour patients are to be maximised.

Presentation 6

Dr Teddy Totimeh, representing a clinical group in Accra, Ghana

Above: Consultant neurosurgeon Dr Teddy Totimeh said that, in Ghana, they have the opportunity to look at brain tumour care in new ways and increase awareness.

Dr. Teddy Totimeh trained as a neurosurgeon at Ghana's premier medical teaching establishment and teaching hospital. He has spent additional time training in Israel, the US and Kenya. He is currently a consultant neurosurgeon at the Greater Accra Regional Hospital and a part-time lecturer in neuro-anatomy. He also runs nationwide symposia on head trauma and primary trauma care. A gifted writer, and a keen observer of the human heart

Photos by MVF Studios

Above: Teddy Totimeh: "We can harness many voices across Africa."

and battles of being, Dr Totimeh has published volumes of essays, short stories and a book of poetry. He blogs regularly on Linked In Pulse.

"Ghana is the gateway to Africa," Dr Totimeh said, and added with an engaging smile that he also considers Ghana to be the centre of the world. "Ghana is on the Greenwich Meridian where it crosses the equator and so geographically qualifies as being the centre of the world."

Accra, the capital of Ghana, is a place that is radiating regional change and increasingly is a city where learning, teaching, and mentorship take place, with the effect of the location representing a synergy of bright minds.

"We are competing with infectious diseases and other challenges in Africa, and we have the opportunity to look at brain tumour care in new ways and increase awareness to give it a place on the government and public agenda," Dr Totimeh said.

Dr Totimeh and his team have a three-fold vision for brain tumour patients in sub-Saharan Africa:

1. harnessing the brain tumour community's collective ability

2. encouraging a renewed focus on conducting and publishing brain tumour research

3. creating bridges with the wider world for training, equipment and patient support strategies

Accra is well positioned to ride the new tide of health investment. Dr Totimeh explained that Ghana is at a stage where more money is going into private health so it may be a very different, more positive picture in the coming years.

Private investors are driving much of this change, although collaboration is needed to ensure that new privately financed cancer services are fully staffed and sustainable.

One of the main challenges faced by the neuro-oncology community in sub-Saharan Africa is that brain tumours are not a high priority for funding. Rather, infectious diseases have the ultimate draw. The lack of funding and resources not only limits the capacity to treat brain tumours, it also saps the motivation of those who want to bring about positive change.

Presentation 7

Prof Nimrod Juniahs Mwakitawha Mwang'ombe representing a clinical group in Lome, Togo

[Editor's note: Due to unforeseen circumstances, Prof Nimrod Juniahs was unable to attend the S-SANOC planning meeting at the last minute and so gave his presentation via a pre-recorded video.]

Prof Nimrod Juniahs Mwakitawha Mwang'ombe is Head of Surgery at the University of Nairobi and Program Director of the Neurosurgery Residency Training Program at Kenyatta National Hospital in Nairobi, Kenya. He is also President-elect of the Pan African Association of Neurological Sciences.

His research interests lie in the fields of Paediatric neurosurgery,neuro-oncology, CNS infections and neurocritical care.

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Above: Prof Nimrod Juniahs Mwakitawha Mwang'ombe is based in Nairobi, Kenya and is Director of the Neurosurgery Residency Training Program at Kenyatta National Hospital

It is generally known that brain tumours are responsible for 2% of all cancer deaths and are the most common solid tumour in young patients, representing 20% of childhood cancers. However, there is difficulty in gathering information in sub-Saharan Africa, resulting in underreporting and fragmented data. The increasing expectations on health services, despite limited funding, serves to further compound this problem.

Professor Juniahs authored a research paper which sought to gain an accurate picture of brain tumours in Kenya and which reviewed and analysed all available existing brain tumour-related data from 1971 to 2005. The research was carried out at Kenyatta National Hospital tertiary referral centre in Nairobi, which has a total bed capacity of 1,800 and hosts a neurosurgical unit.

The research showed that the rate of new brain tumours in developed countries is approximately double that of developing countries. This is possibly due to under-diagnosis although it is thought that ethnic differences may alter the susceptibility to the development of brain tumours.

"We discovered that the majority (60%) of astrocytomas diagnosed in Kenya are in the under-30s, and nearly all ependymomas (99%) are found in under-10s," said Professor Juniahs. "Astrocytomas are the most common tumour type (37.9%), followed by meningioma (34.4%). What is of significance are the very low numbers (2.8%) of metastatic brain tumours (those spread from other cancers) in Kenya, which is a common finding across Africa."

Professor Juniahs explained that studies comparing brain tumour incidence have consistently shown lower incidence in Africans compared to European populations. Several research papers conducted over many years have made this same observation in both malignant and so-called benign tumours. Research published in 2011 showed that young native-born Israelis of Ethiopian descent had a similar risk of brain tumours to those of Israeli children of non-Ethiopian descent. This study, therefore, suggests that the environment has a role to play.

"Further research has since shown that there is a higher rate of brain tumours in black people living in America than in those living in Africa. Rather than being solely due to genetic differences, tumour incidence among immigrants increases when they move to a richer nation and these differences are presumably due to changes in lifestyle or environmental risk factors."

In Africa, paediatric brain tumours represent the most common solid tumour of childhood. Occurring at a rate of three to five new cases per 100,000 children each year, medulloblastoma and low-grade glioma are the most common types, which is similar to elsewhere in the world. Specific data from Kenya show that the average age of diagnosis for brain tumours in the posterior fossa (the lower, rear brain regions) in children is 6.7 years. Brain tumours are more common in girls (a male-female ratio of 1:1.8).

Professor Juniahs said that:

- **primary brain tumours are common in Africa**
- **they account for a large disease burden in a young population and**
- **rates of diagnosis are increasing – which will hopefully translate into improved outcomes in the future**

The way forward, he added, has two key elements:

1. Setting up a cancer registry in Kenya and other African countries will enhance the level of management of brain tumours in Africa and developing countries.

2. The formation of cross-country collaboration will play a major role in improving the healthcare management of brain tumours in this region.

There is a need to develop multi-disciplinary teams for brain tumour care across the entire sub-Saharan Africa region. There also needs to be a concerted effort to collect brain tumour data, especially now that diagnostic and surgical capacity is increasing.

Photos by MVF Studios

Introduction to the S-SANOC African Brain Tumour Patient Organisation Presentations by Christine Mungoshi (Zimbabwe Brain Tumour Association/ZBTA)

Above: Christine Mungoshi, Director of the Zimbabwe Brain Tumour Association, played a pivotal role in the genesis of the S-SANOC planning meeting

Christine Mungoshi is the Director of the Zimbabwe Brain Tumour Association (ZBTA). She helped found the ZBTA after her daughter Paidamoyo was diagnosed with a brain tumour. In her efforts to seek treatment for her child she was confronted with many challenges as there was limited information on brain tumours, and no equipment available in the country to treat her daughter's tumour. With only three neurosurgeons serving fourteen million people at that time the situation was dire.

Christine is a social worker by profession, and committee member of the International Committee of the British Association of Social Workers (BASW). She is about to complete her MSC Palliative Care Degree with De Montfort University (part time) in the United Kingdom.

"Brain tumour patients in sub-Saharan Africa have been suffering for a long time and they need firm representation to improve on the current situation," said Christine Mungoshi, Director of the Zimbabwe Brain Tumour Association.

"I understand the pain of having a loved one suffer from a brain tumour. This journey is personal to me. I lost my daughter Paida to a brain tumour. She was the pearl of my heart. No parent can ever think of burying their child, but when it happens it is very painful. It means you bury your dreams for them, the future you imagined for them, all the expectations - it is agonizing. I still follow my daughter's age mates and try to imagine her life alongside their milestones. I look at her peers, some of whom have now graduated from college, and I wonder how she could have been.

"I always feel my daughter's situation could have been different if she had access to proper medical care. The brain tumour journey is different for those who have proper medical care. What could have happened if she had access to such care? She went through unnecessary pain. Whilst it is not always easy to talk about it, I feel it is important to talk with someone, or with one another to share our stories."

Putting the sub-Saharan Africa brain tumour situation into a global context, the region falls way below expected standards. According to the World Health Organisation: "the highest attainable standard of health is a fundamental right of every human being". And in sub-Saharan Africa the fundamental right to health is not being met by many countries, Christine said.

"Some people in sub-Saharan Africa have zero chance of survival after a brain tumour diagnosis. According to a World Federation of Neurosurgical Societies 2016 report, Sierra Leone, Central Africa Republic, Lesotho and South Sudan have no neurosurgeons. The Democratic Republic of Congo has four neurosurgeons with a population of 74.8

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Above: Christine Mungoshi gave an impassioned address about the situation for brain tumour patients and caregivers in sub-Saharan Africa

million, whilst the UK has 220 neurosurgeons with a population of 64.6 million people. We don't even know how many brain tumour patients there are in sub-Saharan Africa as the region does not have up-to-date brain tumour statistical data."

Christine shared the story of an eight-year-old Zimbabwean girl called Joyce who was diagnosed with a brain tumour.

"Joyce travelled to a hospital where they inserted a shunt. They then sent her back home and she was well, but couldn't afford more treatment. In 2010, however, Joyce started to experience seizures. She had a scan, which showed the tumour had grown and she needed surgery as soon as possible. Since her parents were peasant farmers, they failed to raise money in time. When they finally raised the money required, Joyce eventually had surgery late in 2011 and surgery was followed by some radiotherapy sessions.

"But events then took a disastrous turn when the only radiotherapy machine in the country broke down while Joyce was due to undergo follow up radiation therapy. Joyce sadly died in July 2012. We feel she would have had a chance of survival with adequate resources and timely treatment. We know we are not going to save everyone, but if everyone could have a chance of treatment then that would make a huge difference. We feel that a lack of resources and the system failed Joyce.

"We are all here at the S-SANOC meeting because we care. Each and every one of us is here because we want to make a change.

"I am making a call to you, so that we can be strong and, together, we can reduce suffering in sub-Saharan Africa. Some will say it is an insurmountable challenge, but I want to remind you of the HIV/AIDS situation. People said there would never be a cure, but look at what happened – the successes and the differences made – when people came together. In communities, cultural attitudes towards HIV/AIDS are changing. Once, traditional physicians were recommending people not to use condoms, and that having sex with a young girl would cure you. Today, the situation is different as people have faith in their health systems' ability to treat HIV/AIDS. People's perceptions are changing and HIV/AIDS has been reduced to a chronic disease. Such a transformation could happen for brain tumours."

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The Patient Advocacy Presentations

Irene Azong-Wara:

Jacob's Hope Foundation, Cameroon

Above: Irene Azong-Wara (pictured above centre) has devoted her substantial energy and creativity to improving the situation for people in Cameroon with brain tumours and other cancers

Irene Azong-Wara from Cameroon is the founder of Jacob's Hope Foundation, which became an established community-based organisation in 2016. The organization focuses on advocating for patients while creating opportunities for them to have better access to health care and information. Their mission is to promote prevention, better health care, socio-economic development, discourage harmful traditional practices and adopt behavioural change communication. Their target audiences are women, children, community-based organisations and policy makers.

The idea for Jacob's Hope Foundation started in 2014 when Irene Azong-Wara's father (after whom Jacob's Hope Foundation is named) was diagnosed with a brain tumour. Describing their journey, Irene gave a moving account of how difficult it was to get treatment for him.

Surgery was not an option and there was only one radiotherapy machine in the country, which also serves other neighbouring nations. Health personnel were overloaded with the massive patient inflow and extremely long waits for radiotherapy were the norm.

"You would arrive at 6am and wait until 6pm. Bribery and corruption were used to get a ticket for treatment," Irene said.

Her father received 36 radiation treatments over four months, but the radiotherapy machine was broken for two to three weeks at a time. Equipment would frequently break down, meaning that a day's wait for therapy could result in non-treatment. Pain relief such as morphine was also in short supply and only available to patients in the Cameroonian cities of Douala, Yaoundé and Bamenda.

Irene Azong-Wara showed photos of the overcrowded hospital waiting area and antiquated radiotherapy machine, which appeared to be held together with adhesive tape.

These challenges motivated her after the struggles she and her father faced.

"How can we make a change? How can we make waiting interesting?" These were two of the first questions she asked herself when she was establishing Jacob's Hope Foundation.

The three goals of Jacob's Hope Foundation are to:

1. raise awareness;

2. create a network of brain tumour patients, medical experts and caregivers;

3. provide patients and caregivers with accurate and understandable information about their brain tumour. This latter goal has presented one of the greatest struggles because results are given in French – and the exact details are unclear.

Jacob's Hope Foundation is a not-for-profit organisation based in Cameroon's economic capital, Douala, where the only centre of care is located. Using communication technologies, such as the WhatsApp messaging smartphone app, Irene carries out the foundation's major activities from Douala. So far, these have included raising awareness, fundraising for painkillers, and offering psychological support.

Social media platforms are useful in brain tumour awareness raising. Sales of t-shirts - which are handmade by brain tumour patients and carry the text 'Cancer does not have a face until it's yours or someone you know' - have helped fund pain relief provision.

Irene said: "I first got women involved – men are hard to recruit. I started an initiative called 'Beat Cancer Generously', where volunteers offer a hair and make-up

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Above: The full attention of S-SANOC participants was on Irene Azong-Wara of Jacob's Hope Foundation as she described the plight of brain tumour patients and caregivers in her country, Cameroon

service to members of the public. There is not a word for cancer in my language. It is a disease without a name."

A body art awareness-raising initiative in Cameroon used images of a naked woman painted head-to-toe with various words that are used to describe cancer in different languages. Professional photos were printed and taken to the radiotherapy waiting room.

Irene said that the photos prompted lots of debate. "We do not come from a culture of reading – but of pictures and storytelling. Brochures aren't read but instead there is power in telling our stories."

Listing some of the achievements of Jacob's Hope Foundation, Irene Azong-Wara said that they had also been able to procure pain relief medications through collaboration with the non-profit organisation Camfomedic eV, which was founded in Germany by Cameroonian healthcare students and Germany-based Dr Ivo Azeh. Irene Azong-Wara was also inspired by a fund-raising concept she first saw in Ghana.

"Women make accessories while waiting for treatment which are sold to buy painkillers. Providing a constructive way to use the time spent in a waiting room, women are trained in how to hand craft items such as earrings and fans. A cancer awareness walk is also planned for November 2017 and it is our desire to find ways to help the least educated people understand about cancer and brain tumours."

In Cameroon, families affected by brain tumours typically have many unhelpful perspectives about the condition – but these vary between classes and income.

No one talks about it and regardless of background, all families will keep a brain tumour diagnosis secret.

Middle-class, modern, educated families usually travel abroad to France or India for treatment, finances permitting, while families from a traditional/rural background with lower education and income tend to consider brain tumours as witchcraft.

"A brain tumour is 'death by headache', and is believed to mean you are paying back the evil you have done to the community, or someone has bewitched you," Irene explained. "Belief in witchcraft affected my father's journey. Someone came to my father's house to say that an animal was protecting my father. But a dog was later found attacking animals and my father was then told that he would die as a result. It is devastating that people have these beliefs today."

Both rich and poor in Cameroon use traditional healing methods to try to cure cancer. Religiosity is also a strong influence on all sectors of society. Poorer, lower class families often turn to local 'Men of God' for 'deliverance', while the educated middle classes may

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travel abroad – often to South Africa – to seek healing at 'Churches of Deliverance'.

Irene explained that these people are hoping for a miracle, especially those who have low education and income. "Some people are able to raise funds from locals for medical treatment using Facebook as a call for donations, but many people with cancer get to hospital too late."

To powerfully illustrate this point, a photo was shown of a woman who had arrived at hospital with breast cancer that had grown to such a size that it had broken through her skin.

The challenges for treating brain tumours and other cancers in Cameroon are:

- **limited funds**
- **limited access to information - what little is available is in French only**
- **difficulties talking about cancer due to cultural norms**
- **the conflict of modern versus traditional medicine**
- **having access to hospital and doctor referrals – even those with financial means do not know where to go**
- **bridging the gap between patients and doctors, the latter of whom are seen as 'Gods' and the last hope**
- **in the rural communities, people do not even know the difference between doctors and nurses**

Looking towards the future, Irene shared her 'wish list' for a planned Health Fair project.

"I came up with an idea with friends to run health fairs for corporations. Organising and running these events may provide us with potential funding and a way of raising awareness of brain tumours in the middle classes who can afford to pay for healthcare."

In addition to running health fairs, Jacob's Hope Foundation's goals include the creation of 'health kiosks', which Irene described as "information points in local areas so people know where to go for help". Smart technology needs to be adopted to help brain tumour and cancer patients better understand their conditions - for example, a smartphone app that would give information about different types of cancer and what to do.

Longer term, Jacob's Hope Foundation will be seeking the establishment of cancer care and palliative care centres, a chemotherapy centre, and real estate/homes for people affected by cancer.

"Through Jacob's Hope Foundation, we hope we can create jobs, improve quality of life, and make the world a better place."

Bonita Suckling:

Rainbows and Smiles, South Africa

Above: Bonita Suckling (Rainbows and Smiles, South Africa) lost her little boy, Jed, to a brain tumour and has since dedicated her life to helping children with this devastating disease

Bonita Suckling founded 'Rainbows and Smiles' in South Africa in 2009, in memory of her young son Jed who died from an anaplastic astrocytoma. Rainbows and Smiles is a charity dedicated to supporting those affected by childhood brain tumours.

Rainbows and Smiles Foundation is a charitable organization dedicated to providing assistance in the form of emotional, social and financial support to families and caregivers in need when a child or children of that family is/are diagnosed with cancer. This is achieved through coordination with the hospital facilities, social welfare and medical professionals. Bonita naturally has a special interest in brain tumours. Rainbows and Smiles is a team of nine passionate team members and a few volunteers who drive the fight against childhood cancer in South Africa. Four of the mothers who work with the Foundation have lost their children to cancer.

"When my son, Jed, was on his deathbed," said Bonita Suckling, founder of Rainbows and Smiles in South Africa, "I made a promise that I would fight brain tumours for the rest of my life. I want to see the brain tumour community across sub-Saharan Africa collaborate and share knowledge." Bonita Suckling told S-SANOC participants that "Africa needs you!

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"Health advocacy is very different from 'advocacy'," she said. "Whereas 'advocacy' means to 'influence decisions within political, economic, and social systems and institutions', 'health advocacy' is to 'support and promote patients' health care rights, and enhance community health'. At Rainbows and Smiles, we have adopted a human-rights based approach, which is a matter of social justice and gives a voice to the voiceless."

Rainbows and Smiles exists to provide hope, fun and laughter to help families through the childhood cancer journey, while also seeking to give them the best possible treatment options, information and support.

Bonita said: "We do not discriminate on the basis of race, colour, culture, religion, financial status or any other factor. We have a team of passionate advocates and our organisation's achievements to date include:

- **becoming a member of the Cancer Alliance of South Africa**
- **presenting at the 2015 IBTA World Summit of Brain Tumour Patient Advocates in Barcelona, Spain**
- **attending the International Society of Paediatric Oncology (SIOP) 2016 Annual Congress**
- **full registration as a Public Benefit Organisation (PBO) in South Africa**
- **recognition as a Level 1 B-BBEE (Broad-Based Black Economic Empowerment) organisation which is an official government grading that indicates the highest standards of black workforce integration"**

So that Rainbows and Smiles could best focus its resources on meeting the specific needs of patients, their families and caregivers in South Africa, the organisation devised and sent a questionnaire to people who had been affected by brain tumours. An advocacy toolkit was then put together in response to questionnaire replies. The priorities identified for improving the lives of those affected by brain tumours are:

- **gaining access to treatment**
- **diagnosing and treating early (including education of early warning signs)**
- **upholding patients' right to health care, and empowerment for them to voice their needs**
- **improved cancer training and education for healthcare workers, including challenging negative attitudes which make the situation worse**
- **addressing cancer's stigma, because many people still think it is a curse**
- **educating traditional healers**

Above: Bonita Suckling: "Never lose hope!"

- **providing good psychosocial care of cancer patients and their families**
- **re-engineering the health system to ensure integrated cancer services instead of prolonged waiting in hospital for a specialist service**
- **addressing the negative impact of poverty on cancer services, which means some patients cannot even afford to travel for treatment**
- **lobbying for and implementing effective government and non-profit organisation collaboration.**

Bonita Suckling quoted one questionnaire response in particular: "Where you live should not determine the outcome of your treatment". Inequalities in financial and social support for cancer patients, and inequality in cancer care itself, will require workplace policy reform. This is a hope to which everyone can aspire. However for many cancer patients from rural areas in sub-Saharan Africa, this inequality is a stark reality.

The cost of cancer care can spiral for cancer patients and puts their families into poverty.

"We should not lose hope," said Bonita. "We can turn the hopelessness that many face with their diagnosis into a realised hope with joint action and collaboration."

Rainbows and Smiles' branding includes the image of a bumblebee and Bonita explained why.

"We used a symbol of the bumblebee because, aerodynamically, they are not supposed to be able to fly. But - they do! We shouldn't be able to survive after the death of our child, but we do. We fly and we soar."

At the end of her presentation, Bonita showed a moving video - a photo montage of the many activities Rainbows and Smiles organises: individual play

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time with paediatric patients (called "Love Without Boundaries"), craft days at the hospital; fundraising events; brain tumour awareness activities in the community including sporting events/bike rides; awareness talks; generating newspaper/television coverage; and a 'victory ceremony' for children with brain tumours. (The video can be viewed online here: https://youtu.be/1Nz6XLBqenw)

Linda Longwe:

Zimbabwe Brain Tumor Association (ZBTA)

Above: Linda Longwe of the Zimbabwe Brain Tumour Association gave her presentation to the S-SANOC planning meeting by video-link

Linda Longwe is a board member of the Zimbabwe Brain Tumour Association (ZBTA), and the Cancer Association of Zimbabwe. By profession, she is a leadership development trainer and corporate reputation management consultant. She is based in Southern Africa and her company, Linda Longwe International P/L is registered in Malawi, Zambia and Zimbabwe.

Linda is also a trained counselor and recently completed The Spirituality and Practice of Prayer course with Arrupe College. Linda Longwe is a Council Member of the Manicaland State University of Applied Sciences and the founder of Ethics in Enterprise Africa.

"The ZBTA was born out of a brain tumour support group in Harare, the country's capital city, and was originally made up of mostly brain tumour survivors and parents of brain tumour patients," said ZBTA Board Member, Linda Longwe. "They came together to share experiences and discuss the challenges and problems faced by brain tumour patients and their families and caregivers. The members decided to form a body that would raise awareness of brain tumours and the ZBTA is now a registered welfare organisation that seeks to find ways to address the challenges posed by brain tumours in Zimbabwe."

There is widespread ignorance about brain tumours in Zimbabwe. Like many other countries in sub-Saharan Africa, people live with brain tumours and do not seek medical attention until it's too late for treatment. Nevertheless, with adequate knowledge and early diagnosis it is possible for many lives to be saved.

Brain tumours are peripheral to other health challenges such as HIV/AIDS and malaria. So brain tumours are overshadowed by these conditions. Therefore, in addition to disseminating information about brain tumours, one of the ZBTA's key activities is to lobby government to create policies that are favourable to the cause of brain tumour patients. Specifically, the ZBTA petitions the government to retain existing specialist neurosurgeons, as well as promote interest from local medical students to work in Zimbabwe after completion of their studies.

When the ZBTA has the funds to do so, it provides counseling support services to patients, their loved ones and caregivers. It also supports patients receiving CT scans, catheters and shunts, and provides patients with toiletries.

"We co-ordinate support groups and give psychosocial support and help with the cost of hospital visits which are particularly important for those living in rural regions because their families usually cannot afford to attend, said Linda. "We used to provide food for patients, but the government of Zimbabwe has now improved the quality and quantity of food served in hospitals."

As of now, there are only 15 neurosurgeons in Zimbabwe - one neurosurgeon per million people. They are hugely overworked because they are required to attend to patients in government hospitals in addition to running their own practices.

Eighty-five per cent of the population are unemployed and most people have no access to health insurance. Thousands of people have lost their jobs since September 2015 due to the prevailing economic downturn.

General healthcare has a very high cost - a CT scan costs at least US$350 and an MRI costs US$450 - an expense most people cannot afford. A surgical procedure by a private

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practice neurosurgeon can cost up to US$12,000.

Cancer drugs at government hospitals and subsidised pharmacies are a nominal US$5, but there is a serious shortage of drugs. This means scheduled surgical procedures are unlikely to take place on time.

There is also a huge need for patient accommodation in Zimbabwe. A hostel in Harare that provided free lodgings for patients receiving radiotherapy was closed at the height of inflation in 2007, and remains closed.

However, there are glimmers of hope for radiotherapy treatment. Radiation equipment has recently been upgraded although it is only available in two cities, Harare and Bulawayo, which are 431km apart. There are very limited services for brain tumour patients. Surgical equipment remains antiquated. There are no sophisticated treatments, such as Gamma Knife.

The cancer statistics in Zimbabwe are not a true reflection of what is on the ground. Mostly based on those who go to government hospitals, they don't include those who leave the country for treatment (most often in South Africa or India).

The ZBTA is greatly limited by lack of finances and is only able to provide minimal support to patients. It relies on corporate and donor funding, but because the country is going through such a terrible economic crisis, corporate budgets have been slashed. Additionally, Zimbabwe is seen as a challenging place to send money which further limits sources of donations.

Linda explained that she still remains optimistic for the future.

"I see hope in medical missions from overseas. Medical missions come to Zimbabwe to provide eye surgery, heart surgery and cleft lip surgery. Such visits represent an opportunity for brain tumours. One US anaesthetist coordinated a highly successful cleft lip surgery mission. He was a member of a Rotary Club in the USA - part of Rotary International, which provides humanitarian services worldwide. Other teams have come from as far afield as India.

"Brain tumours know no colour, creed or religion. Contrary to media reports, Zimbabwe is a safe country. Should any medical teams consider our plea, ZBTA is more than willing to liaise with Rotary and provide the contact numbers for the medical practitioners who have come to Zimbabwe on medical missions over the past few years. Ours is a beautiful and friendly country with spectacular scenery and sights. Come and help with medical missions!"

Wilson Mugarura:

Uganda Brain Tumour Foundation (UBTUF)

Above: Pastor Wilson Mugarura was inspired to help establish a Ugandan brain tumour patient and caregiver organisation after he was diagnosed with a meningioma in July 2014

Pastor Wilson Mugarura, a brain tumour survivor, is a founder member and vice chairperson of the Uganda Brain Tumour Foundation (UBTUF). He is a trained theologian from Alpha-Omega Seminary, Jinja and Glad Tidings Bible College, Makerere, Kampala, Uganda. He is currently pastoring Rushere Full Gospel Church, in Kiruhura district, Uganda.

Pastor Wilson Mugarura thanked the S-SANOC organisers for his invitation to the event in London and said that he was representing the youngest organisation in attendance.

"I offer life experience in brain tumours," Wilson said. "I was diagnosed with a meningioma in July 2014 and was evacuated to Yashoda Hospital in Hyderabad State, South India. I had a successful neurosurgery on August 14th that year. Since returning to Uganda, I have suffered backache, weakness in the right side of my body, pain in my right shoulder and blurred vision in my right eye. I take medication to prevent epileptic seizures. My symptoms can fluctuate dramatically - yesterday, I was unable to move one leg but thankfully, today I'm fully mobile. In July 2016, I wanted to launch a brain tumour organisation. The concept was completely new in my country, but there was a clear

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Above: Pastor Wilson Mugarura: a priority for the Uganda Brain Tumour Foundation is to strengthen community participation in the care of patients

need given that Uganda has 26 million people with about five neurosurgeons."

The UBTUF was founded by nine members, among which three are brain tumour survivors. It was set up to be a Ugandan non-governmental, charity organization, dedicated to providing support and tailored services solely to anyone affected by any type of brain tumour and their families and caregivers. Three further members have joined. In addition to the survivor's wives, the membership has a wide range of experience and expertise, and includes a pathologist, lawyer/advocate, public health consultant, neurosurgeon, and a senior military officer.

The foundation aims to help major hospitals in Uganda gain access to brain tumour coordinators, quality diagnostic facilities and quality treatment options. A CT scan costs UK£60 and the machine often malfunctions. By 2020 the UBTUF wants to have proper diagnostic centres. It aims to help organise care for brain tumour patients, their families and their caregivers, according to their needs and expectations.

Belief in witchcraft is another major problem, and the UBTUF is hoping to establish and maintain an information resource centre to raise awareness about brain tumours in Ugandan communities.

Strengthening community participation in the care of brain tumour patients is a further priority for the UBTUF. The organisation seeks to encourage and empower brain tumour patients and survivors to participate in their own care to enable them to provide their own solutions and to participate in decision-making about their health and health care.

"We want to empower people, rather than let them live in self-pity," said Wilson.

Given the limited care available in Uganda, the UBTUF also liaises with clinicians, scientists and allied health professionals to undertake fact-finding, research, monitoring and evaluation of brain tumours and related diseases.

"Government intervention helped change attitudes to HIV/AIDS which is an example of positive progress that could be achieved in relation to brain tumours," he said. The UBTUF has the further objective of seeking "to enter into any arrangements with any government or other institutions, or authority, that may seem conducive to the organisation's objectives, or any of them to obtain any such institutions charters, contracts, decree, rights, grants, loans, privileges or concessions that are desirable to the organisation."

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The UBTUF does not want to work in isolation, but to collaborate with multiple brain tumour stakeholders and members of the Ugandan community and international organisations around the world.

More than making sure that brain tumour patients receive treatment, UBTUF's goal is to help them live every remaining minute of their lives to the fullest possible. UBTUF's other goals include:

- **eradicating the stigma of brain tumours**
- **training brain tumour community caregivers**
- **engaging people who can give care ranging from health personnel, families, relatives caring for patients and any other interested people**
- **educating the next generation of brain tumour physicians by encouraging high school students to study medicine and creating interest in medical students to specialise in neurosurgery and neuro-oncology**

Patients in Uganda do not get quick and efficient attention due to the lack of proper diagnosis. Knowledge of brain tumours is poor and they are diagnosed very late, damaging the prospects for the patient's survival. Very few health facilities perform neurosurgery with so few neurosurgical specialists in the country and treatment and diagnostic systems are inefficient.

Wilson Mugarura says he is a lucky man. "Thank God I am among those lucky few who managed to receive surgery. My treatment cost over US$30,000 – for the care I received in Uganda and the surgery in India. I am able to stand before you today, because I was lucky to receive a donation that helped me get brain tumour surgery in 2014. I know of one person who recently died in one of Uganda's hospitals because he could not raise the money needed for treatment. Even the limited MRI and CT facilities are too expensive for most people and in addition to the cost of a CT scan the current cost of an MRI is GB£157."

Wilson Mugarura's personal story illustrates the many challenges UBTUF faces. He was taken to hospital - a 100 km journey - in the back of a pickup truck after collapsing. When he arrived at the hospital at 10am, no doctor was able to see him. On his second day in hospital, he received a basic CT head scan, but there was no one available for another day to interpret the results. On day three, the surgeon arrived, but the staff failed to let the surgeon know about Wilson.

UBTUF receives no government grants or funding, and is wholly dependent on funds raised by its members and the generosity of members of the public.

"We appeal to all who can, to support us so that we fully establish our foundation in Uganda and are able to support those affected by brain tumours in our country. I thank Kathy Oliver, the IBTA, Christine Mungoshi and the ZBTA for the advice and inspiration given to the UBTUF Executive Director during the foundation's inception stages in 2016."

The important work of the S-SANOC project continues. If you have an interest in improving outcomes for brain tumour patients and their families in sub-Saharan Africa, please contact us. And watch our websites and social media for further information about advocacy activities in this part of the world.

"If you want to go fast, go alone. If you want to go far, go together." (African proverb)

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To read the free-access S-SANOC Report in full online, please visit
https://issuu.com/ibta-org/docs/ibta_ssanoc-report_final_20mar2018

Adult Medulloblastoma:

An Orphan Tumor in Critical Need of More Research

Dr Marta Penas-Prado

Associate Professor and Clinical Research Director, Department of Neuro-Oncology, The UT MD Anderson Cancer Center, Texas, USA

Dr Peter Hau

Professor, Neuro-Oncology Unit, Department of Neurology, University of Regensburg, Regensburg, Germany

Medulloblastoma is the second most common cancer in childhood after leukemias. Pediatric medulloblastoma is typically diagnosed between the ages of four to ten.

Research since the 1980s has led to significant improvement in the survival of children with this malignant brain tumor. With the use of radiation to the brain and spine (craniospinal radiation) and chemotherapy, survival of children five years after the diagnosis of medulloblastoma reaches up to 95% in the most favorable prognostic group. Additionally, over the last decade, the scientific community has made great advances in the understanding of the genetic changes and molecular subgroups of medulloblastoma in children. These molecular subgroups are linked to different clinical characteristics and prognoses, and this new information is now leading to the introduction of experimental targeted therapies and stratification based on molecular risk factors in clinical trials.

Medulloblastoma in adults

In contrast, medulloblastoma is a very rare disease in adults and research has been scarce and mostly limited to retrospective studies.

After the age of 16, the incidence (number of new cases diagnosed per year in a given population) decreases dramatically, but it still affects young individuals, typically younger than 40 years of age. The incidence of medulloblastoma in adults is less than one case per million in the United States, and even though data on the worldwide incidence is limited, the number of new cases is likely similar globally. This low incidence means that only about 200 new cases of medulloblastoma are diagnosed in adults per year in the United States, about 300 in Europe, and only a few thousand worldwide.

Above: Marta Penas-Prado

Above: Peter Hau

This is in sharp contrast to the incidence of other cancers in adults, such as invasive breast cancer, or even other malignant brain tumors such as glioblastoma, with respectively more than 250,000 and more than 12,000 new cases per year in the United States alone.

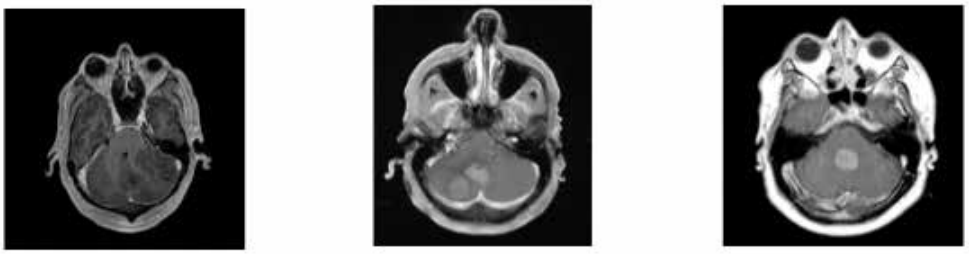
Unfortunately, this low incidence of adult medulloblastoma creates important limitations for research. To date, not a single prospective randomized trial has been performed in adults with medulloblastoma. As a consequence, therapies for adult medulloblastoma are very heterogeneous across different centers and even in the same institution, with treatment guidelines often extrapolated from pediatric experience. Adult medulloblastoma patients, however, are unique in many ways.

Both in children and in young adults, the sequalae (complications) of the disease and therapy can significantly impact their lives in years to come, even if long term survival or a cure is achieved.

At least four molecularly-defined subgroups

The most recent World Health Organization (WHO) classification divides medulloblastoma into at least four molecularly defined subgroups. Two of them receive their name from the activated molecular pathway involved in their development ("WNT" or "wingless", and "SHH" or "Sonic Hedgehog").

Consensus subgroup	WNT-activated	SHH-activated TP53 wild type	non-wnt / non-shh (adults = group 4)
Histology (WHO 2016) (in adults)	Classic, 70%; Large cell / anaplastic, 10-25%	Desmoplatic/nodular (almost exclusive to SHH), 30-40%; MB with extensive nodularity, 3%; Classic, 70%	Classic, 70%; Large cell/anaplastic, 10-25%
Localization	cerebellar peduncle	hemisphere or midline	midline
Age groups			
Gender distribution	♂♂:♀♀	♂♂:♀♀	♂♂:♀
Percentage (in adults)	15%	60%	20-25%
Metastasis	rare	uncommon	30-40%
5-year OS (in adults)	80-90% (large cell worse)	40-50%	40-50% (large cell worse)
Cell of origin	Lower rhombic lip precursors	External granule cell precursors in cerebellar cortex	Midline ventricular matrix precursors
Experimental Molecular therapy	In development	SHH-inhibitors: Vismodegib, Sonidegib, Glasdegib, many others	Unavailable at present
Relapse pattern	Rare	Local	Metastatic
Poor prognostic markers (IHC)	TP53 mutation (12%) Large cell/anaplastic	MYCN amplification (8%) TP53 mutation (13%)	MYCN amplification Large cell/anaplastic



Above: Figure 1 - The known molecular subtypes and characteristics of adult medulloblastomas

Two others are less well characterized genetically and receive a number ("Group 3" and "Group 4"). However, most of the cases analyzed to build this classification were diagnosed in children and not in adults. For this reason, the molecular classification and molecular risk factors in adult medulloblastoma remain less well defined than in children. In adults, only three predominant subgroups are seen (in order of frequency: SHH, Group 4 and WNT), and their molecular markers and prognoses seems to differ from what is seen in children.

We included an illustration (see figure 1) in this article that summarizes the known molecular subtypes and characteristics of adult medulloblastomas.

Treatment of adult medulloblastoma

Whether or not chemotherapy should be part of the upfront treatment of all adult patients with medulloblastoma (as it currently is in children) has been the subject of much debate for decades.

Due to the lack of prospective randomized trials this question remains without a definitive answer. Two recent retrospective studies (a meta-analysis by Kocakaya et al, 2015, and an analysis of the National Cancer Database by Kann et al, 2017) provided valuable data on this issue by demonstrating a benefit on survival with the use of upfront chemotherapy. This benefit is seen not only in high risk patients (incomplete resections, metastatic disease), but also in patients classified as having a lower risk of recurrence, who are often treated with craniospinal radiation alone due to concerns about tolerance to combined therapy.

The German Neuro-Oncology Working Group (NOA) recently published a multicenter prospective trial, which identified the toxicity of chemotherapy in the upfront treatment of medulloblastoma in adult patients (D. Beier, P. Hau et al, 2017). This trial demonstrated the feasibility of this approach, although it also highlighted the considerable toxicity seen in this age group and pointed towards the need for close monitoring during therapy, and perhaps the need for development of modifications to the treatment regimen (attenuated chemotherapy, reduced dose of radiation) to achieve better tolerance.

Collaboration is key

These clear gaps in knowledge need to be addressed, and only collaboration among investigators from multiple centers across the world can make this possible.

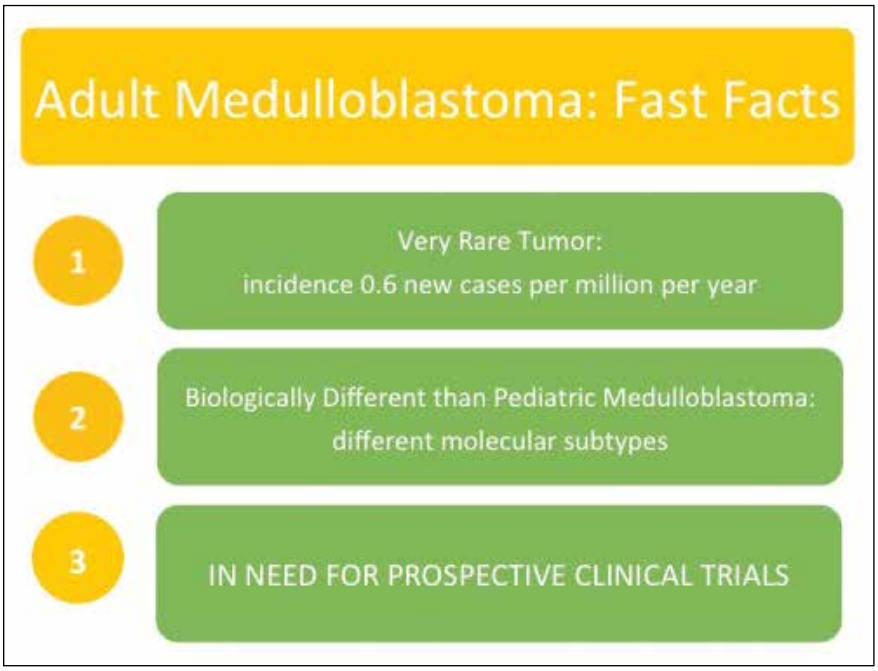
Recently, a consortium of leading clinical and translational academic scientists with a strong track record in research on medulloblastoma has been formed: PersoMed-I.

This consortium was initiated to investigate a personalized risk-adapted treatment and treatment-related biomarkers in adult patients with medulloblastoma. Given the high frequency of SHH tumors in adults and the availability of experimental drugs with potential benefit in this subgroup, the consortium is, in a first project, working on understanding the effect of SHH inhibitors in tumors and their safety in combination with radiation via a Phase 0/Phase Ib trial.

- The Phase 0 trial will consist of the administration of a drug for a short amount of time prior to definitive resection of the tumor, allowing for analysis of a biological response directly in the tumor tissue.

■ The Phase Ib trial will allow the evaluation of possible adverse effects of the combination of reduced craniospinal radiation with an inhibitor of the SHH pathway and determine the safest dose to use.

Once this preliminary data is obtained, a multicenter Phase II randomized trial is planned, which aims to develop a personalized intensity-modulated therapy for adult patients with newly diagnosed medulloblastoma, based on molecular and clinical risk stratification. The trial has been endorsed by the European Organisation for Research and Treatment of Cancer (EORTC) brain tumor group and will be open for cooperation worldwide.



An urgent focus of attention is required

The time to work on the next generation of clinical trials for adult medulloblastoma is now.

The PersoMed-I and additional initiatives in the US by other cooperative groups (Alliance, NRG) are currently under development and require an enormous effort from the scientific community, appropriate support from regulatory and funding agencies, and increased awareness and support from patients and advocacy groups to lead them to success.

We, the investigators involved in adult medulloblastoma research, aim to deliver breakthroughs that will lead to a better understanding of this rare tumor, and more personalized therapies in the future. We would like to express our most sincere gratitude to the IBTA for giving us this opportunity to increase awareness about adult medulloblastoma and the need for international cooperative research in this field. ■

To Learn More about Medulloblastoma and Medulloblastoma in Adults:

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Predicting Risk of Post-Operative Cerebellar Mutism Syndrome (CMS): A BrainSmart Initiative

By Professor David A Walker

Professor of Paediatric Oncology, Children's Brain Tumour Research Centre, University of Nottingham, United Kingdom, on behalf of the Cerebellar Mutism Syndrome (CMS) Nottingham Group

Cerebellar mutism is a key element of the posterior fossa syndrome that complicates up to one-third of patients undergoing cerebellar tumour surgery in childhood. At diagnosis, children with cerebellar tumours can experience:

- symptoms or signs of obstructive hydrocephalus
- focal neurological signs or symptoms of damaged brainstem nuclei or cerebellar structures and connections
- neck pain or head tilt due to stretching of the dura over the swollen brain stem

However up to one third of patients develop mutism or loss of speech within two to seven days of the surgical procedure. This lasts from a few days up to three months before speech returns. On recovery, the speech is almost never fully regained. Patients are left with slowed scanning speech and frequently have slowed global processing speeds affecting all motor functioning, confounding performance in any cognitive testing with a motor component.

Above: Professor David Walker

The patient's and family's experience of this complication is profoundly upsetting at the time and in the long term as it affects their rehabilitation as well as their long-term quality of life as they develop. This personal experience is well described in a series of filmed interviews[1] and published reports[2].

Cerebellar mutism syndrome (CMS), as a post-operative complication, was noted originally by neurosurgeons in the mid 1980s and it has become more apparent with the passing decades. It has been thought that the pressure to achieve complete resection in recent times to enhance chances of cure has been associated with an apparent rising incidence. The precise mechanism for the delayed onset and the profound effect on speech, in children, as opposed to adults, is not explained. It is agreed that it is linked to damage to tracts within the brainstem linking cerebellar structures to the frontal lobes in the cerebral cortex.

This issue was highlighted by Thora Gudrunardottir and colleagues in a series of review articles leading to the formation of the Posterior Fossa Society (www.posteriorfossa.org) which organized a consensus meeting in Iceland in 2015 to agree a definition of CMS[3].

The Nordic countries launched a multi-centre international trial to study the risk of this complication after cerebellar surgery in 2016. The

Below: The CMS Nottingham workshop participants

International Symposium on Pediatric Neuro-Oncology (ISPNO) in Liverpool held the first symposium concerned with CMS in 2016 and the Nottingham University Children's Brain Tumour Research Centre held a workshop in 2017 bringing together eleven international neurosurgical centres to conduct a multi-disciplinary validation process of a recently published predictive risk scoring system[4], which uses anatomical features identifiable on pre-operative scans to assess individual patient risk of post-operative CMS.

Of course, predicting such a risk before an operation is only half the story.

If the predictive risk is low - which it is for the majority - then standard surgery is appropriate. If the predictive risk is high, it poses a particular dilemma as we do not know precisely what aspect of the surgical resection process is the cause of the complication.

A number of hypotheses have been proposed but none have been formally tested. This will be discussed at the planned ISPNO meeting in Denver in July this year. An invitation will be issued to neurosurgical centres to join an international risk scoring network, so as to monitor CMS incidence in each centre and develop experience of scoring the risk pre-operatively in a consistent way so as to inform the impact of preventative strategies in high risk patients in the future as a method of controlling this risk for future children.

We propose this as a BrainSmart strategy to focus on preventing brain injury so as to enhance quality of survival outcomes for survivors of childhood brain tumours. ■

NOTES:

1. Cerebellar Mutism - The discussion. Available from: https://jtvcancersupport.com/?s=cerebellar%2Bmutism

2. Gudrunardottir T, Sehested A, Juhler M, Schmiegelow K. Cerebellar mutism. Child's Nervous System. 2011;27(3):355-363.

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4. Liu JF, Dineen R, Avula S, Chambers T, Dutta M, Jaspan T et al. Development of a pre-operative scoring system for predicting risk of post-operative paediatric cerebellar mutism syndrome. British Journal of Neurosurgery. 2018 [Epub ahead of print].

Professor Silvia Marino - combining clinical work and research as she leads the British Neuro-Oncology Society

Professor Silvia Marino is a leading pathologist in the United Kingdom and the first female President of the British Neuro-Oncology Society. She is the Director of the Brain Tumour Research Centre of Excellence, a partnership between the Blizard Institute at Queen Mary University of London (QMUL), the University College London (UCL) Institute of Neurology and the UK charity Brain Tumour Research (BTR).

The IBTA asked Professor Marino to share some of her thoughts with our international community on the role which pathology is now playing in brain tumour diagnosis and treatment planning.

International Brain Tumour Alliance (IBTA): Where did you spend your childhood?
Silvia Marino (SM): I was born in Turin, Italy and spent not only my childhood but also my early adulthood there. I studied medicine in Turin and then carried out my postgraduate training abroad, in Zurich (Switzerland) and Amsterdam (The Netherlands).

IBTA: Did you come from a family environment that had a connection with medicine or research?
SM: My father was professor of philosophy at the University of Turin and my mother was a teacher of Italian at high school. I would say research has been part of my life from very early on, as it was the main activity of my father although in a very different field. I was definitely fascinated by what research entails, aiming at discovering something new, such as a novel interpretation of a text or a mechanism used by the cells of our body to carry out a specific function.

IBTA: Why did you enter the brain tumour field?
SM: As a thirteen-year-old, I told my dad that I wanted to be an astrophysicist. He tried to look encouraging but also pointed out that it involved a lot of advanced mathematics. I quickly realised that I didn't have a clue about what I was talking about, but exploration of the unknown has always

Above: Professor Silvia Marino, President of the British Neuro-Oncology Society (BNOS)

appealed to me. I have never been put off by a challenge and although astrophysics wasn't for me, I decided on medicine as I was fascinated by biological mechanisms and how these mechanisms can go awry in diseases. Alongside my parents, I have had wonderful mentors along the way; it was a professor at medical school who inspired me to go into brain tumour research.

IBTA: What are the biggest challenges you face in your daily work?
SM: I'm incredibly lucky, here at Queen Mary University of London, as I can balance clinical work with research, although at times it feels as if I effectively have two full time jobs! It is demanding to keep up to date with the clinical practice and to be at the forefront in your research field. It is, however, also extremely exciting and I love that my clinical insight effectively guides my research to be focussed on what is relevant for patients.

IBTA: As President of the British Neuro-Oncology Society (BNOS) what contributions and perspectives are you bringing to this role?
SM: In recent years, BNOS has gone from strength to strength in positioning itself as a main stakeholder in clinical matters related to neuro-oncology. To this end, BNOS has successfully engaged with regulatory bodies, professional groups, brain tumour charities and the wider public.

To achieve a global impact on neuro-oncology, BNOS must engage equally successfully with basic scientists, drive them closer to the BNOS mission and foster synergies between innovative basic science and applied clinical neuro-oncology with the final goal to facilitate a more effective dialogue with the pharmaceutical industry to achieve a substantial positive impact on patients' health. To this end engaging the next generation of neuro-oncology scientists and clinicians in the process, through educational and cultural forums, will be essential.

Above: The brain tumour research team at the Blizard Institute, Queen Mary University, London, UK. The photo was taken on Wear a Hat Day (29th March 2018), a national event which helps raise awareness of brain tumours. Front row (left to right): Silvia Marino, Claire Vinel, Anaelle Dumas, Loredana Guglielmi, Xinyu Zhang, Sara Badodi. Back row (left to right): Gabriel Rosser, James Boot, Peter Hall, Tom Millner, Ash Merve

Because of my dual clinical and basic scientific background, and my long-standing experience in fostering interactions between clinical researchers and basic scientists, my aim is to provide the leadership required for BNOS to accomplish this vision.

IBTA: Please can you briefly tell us about your work in the field of neuropathology?
SM: I am a neuropathologist and, contrary to popular belief, this has very little to do with dead people. In fact most of my work is with patients who are undergoing surgery. Under the microscope, I look at the tissue removed during surgery and I integrate the features I see with the results of molecular tests carried out on this tissue to reach a diagnosis. This diagnosis informs treatment decisions for the patient which are then discussed and agreed at the clinical multidisciplinary meeting.

IBTA: What is the main focus of your research group in particular?
SM: My work is focussed on malignant brain tumours - glioblastomas and medulloblastomas, the most common brain tumours in adults and children respectively. We are addressing the following questions:

- Where do these tumours originate from?
- How do they develop?
- Why are they resistant to therapies?
- Why do they recur?

To address these questions we are studying the cell of origin of these tumours and we are trying to identify novel genes and pathways that control their behaviour.

In particular we are looking at stem cells. These cells are found in every organ and can develop into specialised cells, thus contributing to the maintenance and 'regeneration' of the organ. We find cells behaving as stem cells in tumours too; they play an essential role in "regenerating" the tumours. So killing these cells is crucial. We are trying to establish the difference between these tumour stem cells that keep growing – producing other tumour cells endlessly – and normal stem cells, which stop growing when the body stops needing new cells. If we can understand how a tumour stem cell controls its proliferation, we can start generating more targeted drugs that specifically kill these cells in a more effective and also much less toxic way.

IBTA: What are some of the challenges of establishing and running your own research laboratory?
SM: You need to have a vision and an ambitious one. You need to be excellent at what you do. But you also need to be engaging and a good communicator both scientifically and in lay terms. Because most of us will not have developed all these skills at the same time, you need to be self-confident and take the plunge!

I am the first female President of the British Neuro-Oncology Society and, together with leading my own research centre, I hope I can be a role model for young female scientists. There were very few senior female researchers around when I was training, and it's great to see so many talented and ambitious women coming through over the last fifteen years. A woman tends to have many roles to play, at home and at work, and society needs to support that in order to give the best minds the best opportunities.

IBTA: What is at the top of your wish list for brain tumour patients?
SM: Finding a cure.

IBTA: What inspires you in your research work?
SM: Pushing boundaries, colleagues and patients.

IBTA: How do you relax? Do you have a hobby?
SM: I like trekking and I am passionate about travelling and exploring new places, every now and then though a good spot of shopping is all you need to relax! ■

The IBTA maintains a list of key online clinical trials portals to help patients and caregivers locate clincal trial centres and undersand criteria for joining a brain tumour trial.
For more information, visit www.theibta.org

A New Beginning for Neuro-oncology in Sri Lanka

Ms. Ruvini Abeygunaratne

Consultant Neurosurgeon, Department of Neurosurgery, Lanka Hospitals PLC, Sri Lanka

Sri Lanka (formerly Ceylon) is a beautiful island located in the Indian Ocean in close proximity to India. Also known as the ' Pearl of the Indian Ocean', it has a very vibrant culture.

The people of this island nation are known for their generosity, kindness and open heartedness. With a population of 21 million, and with a very high literacy rate, it is an island in which different religions live in harmony. Unfortunately, in the past, its main reason for being known would have been the bloody civil war, which took place for nearly thirty years. This war finally ended in 2009 and the country is now trying to catch up with the rest of South Asia and is making leaps and bounds in its attempts. Due to the war, certain areas of medical care were marginalized and others took precedence, especially in neurosurgery. The need at the time was management of trauma and all other specialties took a back seat. Since 2009 all efforts have been taken to become on a par with other neighboring nations and to provide the best care possible for our patients.

Caring for patients in Sri Lanka

Healthcare in Sri Lanka is completely free and is run by the Ministry of Health. Due to the high volume of patients and limited resources there are several private institutions, which buffer the system as well. There are twenty consultant neurosurgeons (very few completely in the private sector) in Sri Lanka. The required number to cater to the population is calculated to be around one hundred so as you can see this is the first hurdle.

Secondly, there are eight neurosurgical units in the country, with the main one based at the National Hospital in Colombo which has the most resources. Most of the other units, apart from two, are one-man bases. So caring for the volume of patients with limited resources is extremely difficult. Most patients get transferred to Colombo and stay on a waiting list to have their tumors operated upon, which is not ideal for tumor management. The distance which the patients and families have to come for treatment also has a significant impact on compliance, and affects follow-up management and adjuvant treatment.

Above: Ms Ruvini Abeyguaratne

Thirdly, and most importantly, there is only one main cancer hospital in Sri Lanka and that is in Colombo, so the logistics of patients travelling the distance for treatment, as well as completing treatment and coming back for follow-ups, falls rapidly.

Fourthly, as neurosurgeons and neuro-oncologists practicing western medicine we have to compete at times with an indigenous medical system that people turn to in times of need. Ayurveda is more than 2000 years old and works in certain conditions. Directing patients to traditional methods is a problem for the care of people with brain tumors and also a reason why they are lost to follow-up.

Finally the lack of keeping up with evidence-based medicine is a challenge so the information given to the patient with regards to care available may not be up to date and may discourage patients from seeking treatment.

Things are changing

It is a common occurrence that a picture of 'doom and gloom' is painted for the patient by the clinician when a brain tumour diagnosis is made and the patient is not even referred for a neurosurgical opinion. When it comes to brain metastasis most patients are sent straight for radiotherapy. The lack of a multidisciplinary approach was unheard of since recently and working as a team was a rarity. This is, I assume, cultural. In Sri Lanka, the lack of a fully functioning database and recalling patients back for follow-up is also a logistical problem. This results in patient follow-up and surveillance becoming the responsibility of the patient and family which seems completely unfair during the difficult time they are going through.

But, things are changing for the better! So all is not doom and gloom. I arrived in Sri Lanka in 2012 due to personal reasons. To help my country in whatever way possible, I had done my neurosurgical training and worked as a consultant neuro-oncology surgeon in the United Kingdom. Things were difficult when I arrived in Sri Lanka. Although I am originally from Sri Lanka I had trained elsewhere and my main aim was to make changes without alienating or stepping on toes. As a woman and a surgeon, treading lightly wasn't really my forte! So I had to make changes. Firstly it was a matter of getting all the neurosurgeons

Above: A lush rain forest in Sri Lanka

Above: A beautiful beach in Sri Lanka with crystal clear waters – paradise!

together, sitting together and talking. Some were responsive, while others were extremely reluctant.

The SNO Wilkins-Barrick scholarship – a tool for improving care

What we needed was an excuse, so taking this into account I applied for the SNO Wilkins-Barrick scholarship to carry out a neuro-oncology course in Colombo. This was to achieve two main goals. The first goal was to get everyone working together and the second was to highlight neuro-oncology in Sri Lanka. We were awarded the scholarship in 2016 and had an extremely successful course in January 2017. The course faculty included some of my friends in the neuro-oncology fraternity in the UK. Surprisingly the course was over subscribed and we ran out of space and food. It was attended by neurosurgeons, radiologists, neurologists, oncologists and even pathologists.

With this and the collaborations established, we set up a multidisciplinary meeting, which happens every two weeks to discuss difficult and challenging cases. This is attended by neurosurgeons who want to discuss cases as well as oncologists and neurologists, radiologists and pathologists.

We were able to appoint a keyworker to maintain a database of patients going through the neuro-oncology services at one of the private institutions. We are now in talks setting up a database nationally.

Education and information provision is key

Patient education is also a very important aspect, which has been neglected for far too long. This is mainly due to the fact that correct information is not being conveyed to patients and their families and up to date evidence is not being passed on about which current treatment options are available. We have started with a national drive to do this via television and radio as well as with written information.

The lack of knowledge appears to be a key factor in patient compliance. The Ministry of Health and the neurosurgeons association of Sri Lanka are collaborating to increase the resources and number of neurosurgeons available in the country. There is a huge and daunting task ahead of us. But looking at the changes already in place, I am confident that we will soon achieve it all. It's amazing what gentle pressure and persistence can achieve.

In the future, we aim to provide our patients with individualized treatment plans, based on their histological, molecular tumor profile and surgical excision. It will be a multidisciplinary approach taking into consideration all the patient's needs and those of their caregivers. We aim to have allocated key workers for patients who will be available to them throughout their treatment and beyond, and will also organize follow-up care.

I believe that providing this supportive network makes a lonely, frightening journey less lonely and less daunting. ■

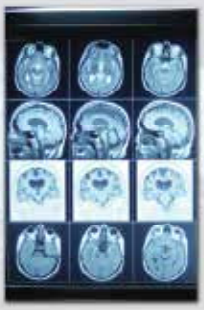
JACOB'S HOPE FOUNDATION

- 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

MUSELLA FOUNDATION FOR BRAIN TUMOR RESEARCH & INFORMATION

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 payment 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

ERN EURACAN

European Reference Networks

A unique network of all **rare adult solid cancers** corresponding to the RARECARE list of rare cancers based on the ICD-O

Achievements

- "**Virtual" advisory board** of medical specialists
- **Homogenisation** of Clinical Practice Guidelines;
- **Training and education** activities organised within the 10 domains

Unique ERN model

Vision for 2018-2019

- Implement "**roadmaps**" for referral and self-referral of adults with rare solid cancers to expert centres;
- Promote **telepathology** (diagnosis review) and teleconsultations;
- Initiate and promote novel **translational research programmes** and associated tools: multinational databases and tumour banks;
- Additional **affiliated centres**, patient representatives (known as "**ePAGS**") and **scientific societies** will join EURACAN in due course to further extend the network's outreach and increase coverage.

Centre Léon Bérard - muriel.rogasik@lyon.unicancer.fr http://euracan.ern-net.eu @ERN_EURACAN www.facebook.com/EURACAN/

Top 10 Tips for a Successful Walk for Brain Tumour Awareness

25 years of walk events keep Brain Tumour Foundation of Canada moving forward

Carla Garrett
Brain Tumour Foundation of Canada

Above: Brain Tumour Foundation of Canada's London, Ontario 2017 walk where more than CAD $200,000 was raised by 929 registrants

If you want to raise funds or awareness for brain tumours, a walk is a simple yet effective way to engage a community and bring hope to people living with a brain tumour.

With over two decades of experience organizing walks, Brain Tumour Foundation of Canada has learned a thing or two over the years about organizing a successful walk to raise awareness of brain tumours.

This year, the foundation celebrates the 25th anniversary of its first brain tumour walk in Canada. The annual fundraiser is essential to our work, bringing in much-needed funding and awareness of brain tumours. Last year, the annual Walk program raised $1.8 million for the foundation with more than 8,000 participants from 21 cities across the country.

"The unique thing about our brain tumour walk events is that they are more than a fundraiser. They bring people together and create a positive experience for everyone," said Suzanne Fratschko-Elliott, Fundraising and Engagement Manager for Brain Tumour Foundation of Canada.

Working with an amazing team of dedicated volunteers, the walks have evolved and gained momentum each year with the injection of new ideas and by sticking with what works. Whether you are a survivor, a group of healthcare professionals or an individual just wanting to raise more awareness, follow these top ten tips to organize a brain tumour walk in your community:

1. Talk to everybody

You may be surprised at how many people know someone with a brain tumour and what connections they may have to support your event. Janet Hempler, walk coordinator in Edmonton, Canada discovered this when she made a friend through her support group who knew someone in radio. This relationship led to a five-year arrangement for free advertising and a second TV interview to promote the walk. Don't be afraid to share your story and tell others why this cause is important to you and invite them to join you. Stay engaged with contacts from previous years and build those relationships with genuine thanks for their support year-round.

2. Focus on the goal

Awareness, fundraising or better yet, both! Set realistic goals and keep them as simple as signing up teams and raising money. Revisit your goals and strive for targets to keep people motivated.

3. Use social media

If you can't talk to everyone face to face, be social with social media.

Above: Brain Tumour Foundation of Canada's Vancouver, British Columbia awareness raising walk attracted 489 participants

Above: The sun shone down on Vancouver, British Columbia where CAD $72,000 was raised during the Brain Tumour Foundation of Canada's walk there

Above: Add some additional fun to your brain tumour walk - perhaps some face painting!

Use social media to connect with volunteers and participants. Keeping everyone in the know on what to expect at the walk will make them feel welcome and part of the community. If people feel connected to the cause, they will come back. There are also a million ways to advertise your event with social media. If you have a social media guru on your committee, you are gold!

4. Be diverse

Build an organizing team with a diversity of interests, skills and motivations. Karen Metcalfe, who has organized the walk event in Windsor, Canada for four years, suggests looking beyond family and close friends. "This will allow your team to carry on for years to come and it brings in new ideas and new connections," she said.

Having a diverse team will ensure success because burnout is real and life can take people in different directions. People shouldn't feel guilty about taking a break if they need to.

5. Listen to stories

Always make time to listen. Recognize the different experiences and stories people will bring to your event. Everyone has a story they want to embrace on walk day, whether it's to celebrate a survivor, to honour someone in treatment or to remember a loved one. Ask for permission to use some of these stories in the media to spread more awareness of brain tumours in your community.

6. Have some fun

Keep hope and positivity flowing through the crowd with some entertainment. Build the event to be a fun place for families where they can make memories and connections. Hire a local band to play and encourage their fans to sign up for the walk. Give people a reason to stay.

7. Communicate the impact

Everyone wants to know they are making a difference! Be sure to thank your sponsors and donors with a photo of survivors or of the people who won their donated items. Recognize your volunteers and how, if a fundraising event, the money your teams raised will impact the brain tumour community.

8. Make it local

Get your local community involved. Approach businesses for support and promote them alongside your event. Engage service clubs and local schools too.

9. Divide and conquer

Divide the tasks. Don't do it alone. If you have talented people, let them use their ideas. Give each member of your organizing team a responsibility they can own.

10. Always evolve

Ask for feedback from everyone involved in your walk event so you know what works and what doesn't. Be prepared to change and learn new things as your event grows.

It's not just about what you call your walk, where you hold it or how you advertise it. In fact, the most important thing for a successful walk costs nothing but is priceless - it's about relationships.

"It's the people. Our organizing committee works hard to set up an event where people can connect. Our community is generous in supporting through sponsorship, donations and team support and our participants are generous. We have a wonderful research community in Windsor that comes to the walk and shares the future and hope," said Karen Metcalfe. ■

About Brain Tumour Foundation of Canada

Brain Tumour Foundation of Canada is the only national charity in the country offering information and support to patients affected by any kind of brain tumour – be it cancerous, non-malignant or metastases. The organization funds ground-breaking research across North America and, since 1982, has dedicated over CAD $5.8 million to finding a cure and improving treatment for brain tumour survivors. Brain Tumour Foundation of Canada is funded solely through generous contributions from individuals, corporations, organizations, employee groups and special events. Learn more at Brain Tumour Foundation of Canada's website: www.BrainTumour.ca

ISPNO 2018 - a great forum for collaboration and exchange of information

The 18th International Symposium on Pediatric Neuro-Oncology (ISPNO) – a unique forum that brings together leading researchers, physicians, surgeons, nurses, and social workers to exchange information and results and collaborate – will be held in Denver this summer. ISPNO is the major global meeting of the international community of professionals involved in the scientific research, diagnosis, treatment, and rehabilitation of infants, children, and young people with central nervous system (CNS) tumors.

"The Symposium is critically important for researchers around the world. It provides a forum for the thoughtful exchange of information and many opportunities to further collaborative efforts, both of which will lead to more promising studies that we can use to help our patients," said Nick Foreman, MD, ISPNO conference co-chair and Associate Chief of the Center for Cancer and Blood Disorders at Children's Hospital Colorado.

The Symposium will take place from June 29 to July 3 at the Hyatt Regency Hotel in downtown Denver. It will include plenary and poster sessions, keynote talks, and roundtable discussions about the latest research and clinical care of pediatric CNS tumors.

More than 1,500 pediatric neuro-oncology specialists from around the world will come to Denver to engage in dialogue regarding new treatments, innovative research, and advances in pediatric neuro-oncology.

ISPNO FAMILY DAY

In addition to the main scientific sessions, ISPNO 2018 also includes sessions for families, nonprofits, nurses, and social workers.

Survivors, families and caregivers are invited to attend ISPNO Family Day on June 29th at the University of Colorado Anschutz Medical Campus in Denver. ISPNO Family Day will include a full day of programs specifically created for families of central nervous system tumor patients and will cover a wide range of topics, including research updates, education issues, nutrition and wellness, caregiving, and creating a family's "new normal." A special, specific track for adolescents/young adults battling cancer will be offered, and there will also be a special breakout session for grieving families.

Following the Family Day sessions, attendees are invited to Children's Hospital Colorado for cocktails and networking followed by dinner. This is an opportunity for families, patients, friends, and non-profit partners to gather and get to know one another after a day of learning.

Family Day is free for cancer families to attend. There are a limited number of travel scholarships available.

A wide range of special sessions is on offer at ISPNO

Activities on Saturday, June 30th include the Non-Profit Collaborative, Social Worker and Nursing Sessions, and Compassion Fatigue Workshop.

The Non-Profit Collaborative provides an opportunity for charitable organizations from around the globe to engage in lively, interactive sessions that will highlight partnership best practices within the pediatric cancer and international brain cancer communities. Participants will also engage with world-class researchers in a meaningful way, with the aim of identifying opportunities to enhance research productivity through non-profit partnerships and alliances.

The ISPNO Denver Nursing Symposium will continue to build upon nursing professionals' growing presence at each ISPNO and will feature speakers who are experts in pediatric neuro-oncology clinical care. The Nursing Session concludes with a social gathering giving nurses the opportunity to network and plan for future collaborations.

Similarly, the Social Worker Session will address the unique experiences of pediatric neuro-oncology social work professionals including educational needs, whole-patient care, bereavement programming, and research opportunities.

The Compassion Fatigue Workshop will explore the challenges and suffering that caregivers can often experience as they work with cancer patients and their families. The session will address mindfulness, self-compassion, enhancing personal and team support, and the use of gratitude as powerful techniques to build resilience and lessen compassion fatigue.

The Symposium is held every two years and alternates locations in Asia, Europe, and North America. Held in Liverpool, United Kingdom in 2016, this is the first time the symposium will be held in the United States since 2008. ■

For additional information AND TO REGISTER, please visit ISPNO2018.com.

Plan your 2018 "Walk Around the World for Brain Tumours" now!

For further information, contact kathy@theibta.org

A new neuro-oncology survivorship plan for brain tumor patients and their families

Heather E Leeper, MD, MSc
Division of Neuro-Oncology, North Shore University Health System, Evanston, Illinois, United States

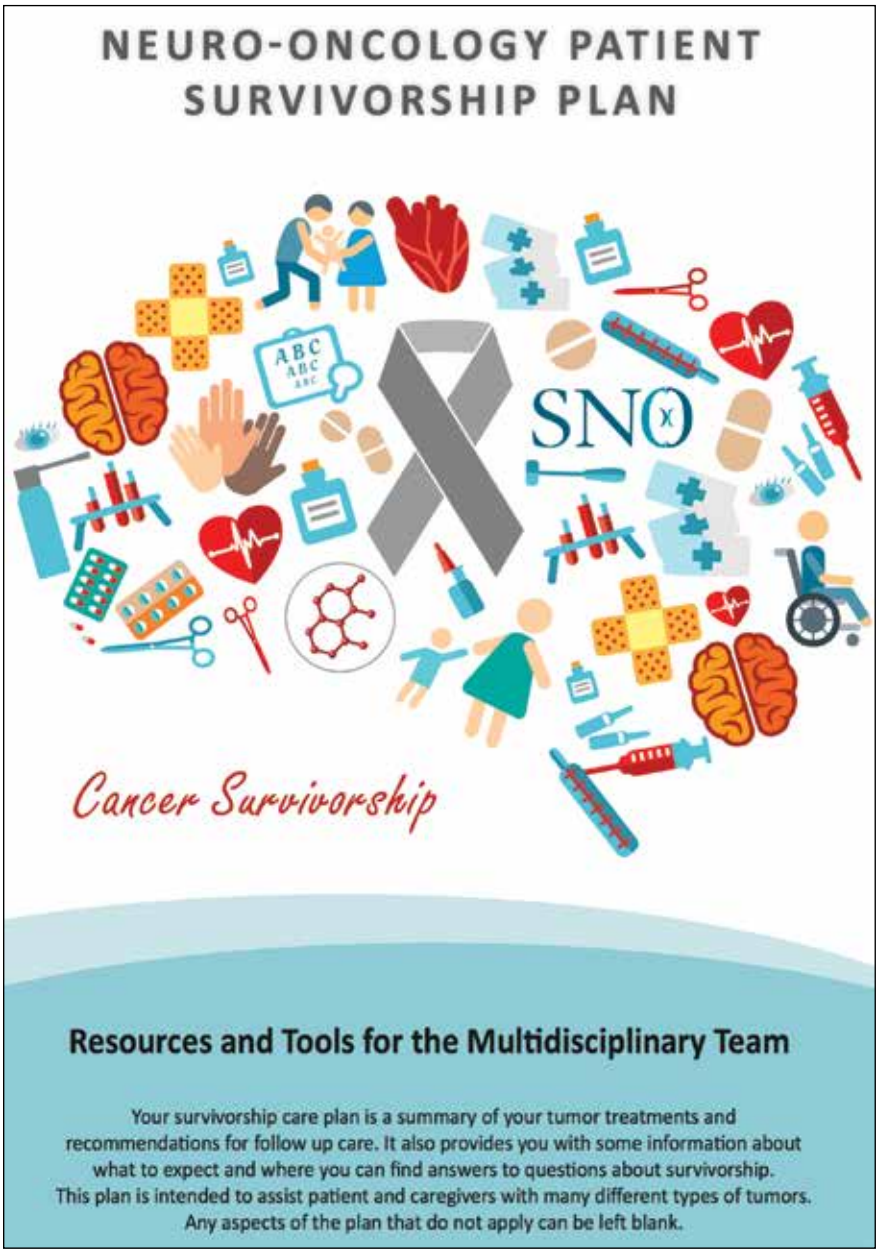
A neuro-oncology patient specific survivorship care plan has been created for adult patients diagnosed with and treated for a primary central nervous system tumor. It is endorsed by the Society for Neuro-Oncology (SNO) and is available as a fillable PDF at https://www.soc-neuro-onc.org/SNO/Resources/Survivorship_Care_Plan.aspx

As explained on the SNO website: "Cancer patient survivorship has become a significant topic within oncology care for both adult and pediatric patients. Starting in 2005, the U.S. Institute of Medicine recommended the use of survivorship care plans to assist patients transitioning from active treatment to the post-treatment phase of their cancer care, a critical time in many patients' care. Since 2014 there has been a mandate within the U.S. for adult cancer patients treated with curative intent to receive survivorship care plans comprised of a treatment summary and a follow-up plan to facilitate a better understanding among patients of what to expect post-treatment."

The neuro-oncology patient specific survivorship care plan has been collaboratively developed by a multidisciplinary and inter-professional committee and endorsed by the Society for Neuro-Oncology Guidelines Committee.

The neuro-oncology patient specific survivorship care plan is intended to be used as a medical document to begin addressing the complex and variable survivorship care needs among brain tumor patients of all ages, across all diagnoses and anatomical locations within the central nervous system.

Many patients receive multiple types of treatments from several medical subspecialties at different health care facilities, sometimes at considerable distances from each other, while having high symptom burden and significant psychosocial needs. The neuro-oncology patient specific survivorship care plan has been designed, per the recommended guidelines for such survivorship care



Above: The new Neuro-Oncology Patient Survivorship Plan, which is endorsed by the Society for Neuro-Oncology (SNO)

Above: Dr Heather Leeper

plans in the United States, to provide a comprehensive yet concise summary of the following aspects:

- treatment summary
- ongoing supportive care medication list
- list of treating physicians and other medical professionals providing supportive care (physical therapy, for example)
- specific recommendations for continued follow up medical care
- monitoring for recurrence and second cancer
- health and wellness promotion
- genetic testing results if applicable
- fertility preservation details if applicable
- and a range of psychosocial issues commonly experienced by cancer patients with recommendations for patients to be referred to resources such as brain tumour patient advocacy, support and information organisations.

It is hoped these care plans will facilitate communication between patients, their caregivers/families and their health care providers and patient advocacy groups so that patients can experience a better quality of life and less symptom burden. ■

A special thank-you to our great graphic designer, Edwina Kelly (edwina@edwinakellydesign.co.uk), our IBTA magazine printers, The Wyndeham Group (http://www.wyndeham.co.uk/) and our international magazine distributors, Worldwide Mailing Solutions (WMS - https://www.wwms.co.uk/). 2018 marks the tenth anniversary of the IBTA's work with all of these companies. Thanks for a great decade Edwina, Wyndeham and WMS!

Challenges in Treating Childhood Brain Tumors in Latin America

Dr. Diana Osorio

is a pediatric neuro-oncologist leading the global health neuro-oncology initiative at Nationwide Children's Hospital and The Ohio State University in Columbus, Ohio, USA. She is a native-Spanish speaker from Colombia and completed her training in New York, culminating with a pediatric neuro-oncology fellowship at New York University Langone Medical Center.

Dr. Jonathan Finlay

is the Director of the Pediatric Neuro-Oncology Program at Nationwide Children's Hospital in Columbus, Ohio, USA. He is a globally recognized expert in pediatric neuro-oncology, most notably for his work in CNS germ cell tumors and for the development of irradiation-avoiding treatment strategies for young children with malignant brain tumors.

The care of a child with a brain tumor requires a team effort involving multiple disciplines:

- *neurosurgery* to safely remove a tumor;
- *neuro-pathology* to provide the right diagnosis;
- *neuro-oncology* to guide the patient to understand the diagnosis, prognosis, the overall treatment plan, and to administer the chemotherapy;
- *neuro-radiology* to give accurate interpretation of the imaging studies and determine if the child is responding to therapy or not;
- *radiation oncology* to determine and administer the doses and fields of irradiation needed;
- *rehabilitation*;
- *psychiatry*;
- *palliative care* and others

Therefore, one of the greatest challenges in treating children with brain tumors in any country is linked to the inherent complexity of our field.

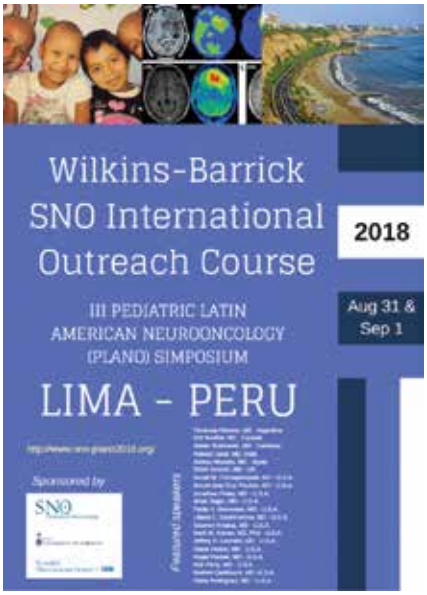
The nature of the challenges

South America includes countries of diverse economical and medical resources, including diverse oncological expertise. In many academic centers in high-income countries like the United States/Canada/Europe, we are fortunate to be able to focus entirely on one aspect of oncology. Oncologists in Latin America are not subspecialized and therefore at any one time will care for children with a whole spectrum of hematological (blood) or oncological (cancer) diseases. Therefore, the responsibility to know the standard of care and latest research for patients with a wide variety of conditions such as bone tumors and leukemias, as well as brain tumors, is a daunting task. Another possible barrier is also that the medical literature is primarily written in English and requires expensive journal subscriptions to obtain them. The field of neuro-oncology thrives on a strong multi-disciplinary effort, which is lacking in Latin America as well.

It was the vision of Drs. Jonathan L. Finlay (then, at the Children's Hospital of Los Angeles) and Ibrahim Qaddoumi (St. Jude Children's Research Hospital, Memphis) to initiate a real-time, tele-conferenced brain tumor board given their experience and measure of success with neuro-oncology program improvements in Paraguay, Central America, Brazil, Asia and the Middle East, respectively.

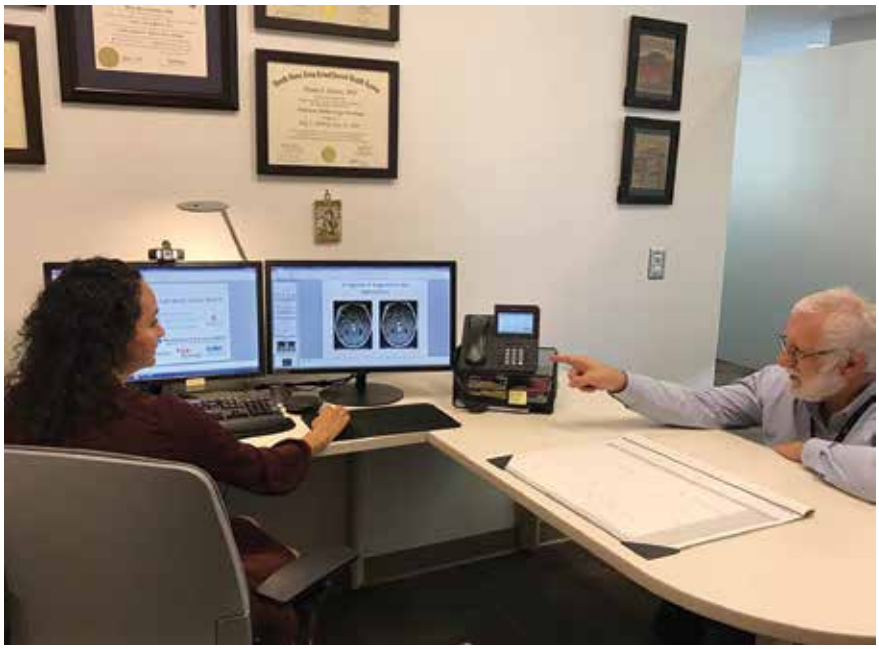
Connecting and combining efforts to improve brain tumor patient outcomes

During my training in 2013, we attended a pediatric hematology/oncology conference in Bogotá, Colombia following which, given my Colombian background and Spanish language proficiency, we initiated monthly meetings with the Hospital Universitario de San Vicente de Paul in Medellín, Colombia. We discussed



Above: A neuro-oncology course will be held in Lima, Peru from 31 August to 1 September, 2018, made possible by a grant from the Society for Neuro-Oncology Wilkins-Barrick International Outreach Course initiative.
For more information http://sno-plano2018.org/
Contact: sno.plano2018@gmail.com

Above: Global Pediatric Neuro-Oncologists (from left to right): Drs. Ibrahim Qaddoumi (St. Jude Children's Research Hospital, Memphis, TN; USA), Jonathan L. Finlay (Nationwide Children's Hospital and The Ohio State University, Columbus, OH; USA), Ute Bartels (Hospital for Sick Children, Toronto, ON, Canada), Diana S. Osorio (Nationwide Children's Hospital and The Ohio State University, Columbus, OH; USA), Alvaro Lassaletta (Hospital Infantil Universitario Niño Jesús, Madrid, Spain), Andres Morales la Madrid (Hospital Sant Joan de Déu, Barcelona, Spain).



Above: Dr Diana Osorio (left) and Dr Jonathan Finlay (right) review a young patient's MRI

their brain tumor patients on a monthly basis, provided management advice and received good feedback. After completion of my neuro-oncology training in 2014, Dr. Finlay transferred to Nationwide Children's Hospital in Columbus, Ohio and recruited me to continue our Latin American outreach with the idea to expand our efforts to the rest of Latin America.

We began including other institutions in Colombia, Paraguay, Peru, Brazil and Argentina, and increased the frequency of our meetings to weekly. Similarly, Dr. Ute Bartels from the Hospital for Sick Children in Toronto, Canada had for several years been cooperating with institutions in Central America, and her trainee from Spain at that time, Dr. Alvaro Lassaletta, worked on these efforts with her. In 2015, we agreed to combine our efforts. Most recently in 2016, Dr. Andres Morales La Madrid, also a native-Spanish speaker from Peru who completed his neuro-oncology training at the Dana Farber Cancer Institute, joined our group and provided several more contacts within South America.

We have thus grown into a cohesive team of six "global" pediatric neuro-oncologists (Figure 1) and hold weekly meetings that include 20 countries in Central America, South America and the Caribbean with over 200 members, predominantly pediatric hematologists/oncologists, but also including other subspecialists such as neurosurgeons, pathologists, radiologists and radiation oncologists. Our main goals are to provide support, education, promote a multidisciplinary approach, provide second pathology/radiology reviews and management advice.

In our meetings, we frequently offer formal second pathological consultations, as the brain tumor tissue is typically preserved in paraffin and transportable via express mail. We have commonly encountered discordance in pathological diagnoses throughout Latin America, attributable to the lack of equipment, resources, expertise in neuro-pathology, the rarity of these tumors and the limited available laboratory infrastructure. Many of the special stains/tests needed to render accurate diagnoses are not available at many of their centers. Depending on patient volume, an institution may only see one to two patients with the more complex diagnoses each year, and therefore it is not financially justifiable to have numerous special stains available - nor will they be able to validate them clinically for their own institutional standards. In parallel, the field of neuro-pathology has evolved tremendously in recent years, with new molecular and genetic technologies further sub-categorizing many tumors we used to classify as single entities (eg: medulloblastoma). This adds another layer of complexity.

More challenges

Fortunately, the diagnosis of a child with a brain tumor is a relatively rare event. In the United States we encounter approximately 4,500 children diagnosed with brain tumors each year. Nevertheless, within the world of oncology, pediatric brain tumors are the second most common type of cancer after leukemia. Unlike leukemia, they are extremely heterogeneous with multiple types and widely different management approaches. This presents a challenge because the rarity of paediatric brain tumors provides a certain unfamiliarity with how to treat a child with a brain tumor based on low numbers and experience.

Insurance companies also do not facilitate matters. Early in our interventions,

I remember we discussed one young child from the region who underwent an excellent surgical removal of his brain tumor confirmed on his scans (which is no easy task!) and pathology found this to be an ependymoma. The treating oncologist requested to know the next steps which we advised to be focal radiation therapy. Unfortunately, it was not until several months later that the child initiated radiation therapy. Our understanding was that insurance dictated where the child would undergo treatments, which contributed to significant delays in his therapy. This delay in radiation therapy likely contributed to the tumor eventually recurring, at which point it becomes incurable. This was extremely disheartening given that the resources and expertise are in place to provide a cure, but it was the inability to "connect the dots" in a timely fashion that became the barrier to his potential cure.

It is especially common in Latin America that the primary oncologists are unable to oversee the care of their patient in its entirety and provide care in as timely a fashion as possible. Neuro-oncology is a field where typically a surgery for a malignant, fast growing brain tumor occurs almost immediately, and there is a two to four week window to initiate more definitive therapy (whether it be chemotherapy or radiation therapy or both). Delay becomes a critical disadvantage to cure.

Sophisticated neurosurgical techniques that optimize surgical resection and minimize toxicities of surgery are also not available in every country. Sedated procedures can also be a luxury – and this becomes a challenge in a population of children who need magnetic resonance imaging on a routine basis. Socially, we have also encountered families who do not understand that treatment is needed once a tumor is completely removed or that a slow growing tumor needs treatment to prevent it from causing physical and/or intellectual deficits.

Education is key

Thus far, the solutions we are able to provide to these multiple barriers to brain tumor care start with education. Education through email communications and real-time weekly meetings, with open discussion in Spanish, is followed by the preparation of summary reports written in Spanish to solidify what has been discussed, which are then distributed to all participating members, usually with relevant scientific papers that support our recommendations.

Likewise, we have been fortunate to be able to provide neuro-oncology courses, most recently one at the Hospital Sant Joan de Déu in Barcelona, Spain, thanks to the Lionel Messi Foundation and organized by Dr. Morales la Madrid and his colleagues. Another was held in March 2018 in the Hospital GRAACC, São Paulo, Brazil, through the Society of Neuro-Oncology Latin America (SNOLA) and organized by Dr. Andrea Cappellano. Later this year, there will be yet another course in Lima, Peru, thanks to a grant awarded to the oncologists of Lima and us by the Society for Neuro-Oncology (SNO) (see poster image on page 54).

We find that our efforts are well-received and we hope to continue to expand and improve these efforts, bridging a gap in the care of children with brain tumors, making such care more accessible and providing an educational and informative life-line to subspecialists throughout Latin America. ■

RARE CANCERS EUROPE (RCE) is a multi-stakeholder initiative dedicated to putting rare cancers firmly on the European policy agenda and to identify and recommend appropriate solutions to the many challenges faced by people with these diseases.

At the European Society for Medical Oncology (ESMO) conference in Madrid in 2017, representatives of the various partner organisations involved in Rare Cancers Europe (pictured above) met to discuss a wide range of issues for the over four million people in the European Union affected by a rare cancer. These include late or incorrect diagnosis; lack of access to appropriate therapies and clinical expertise, very limited number of clinical studies due to the small number of patients, few available registries and tissue banks, etc.

There are more than 500,000 new cases of rare cancers diagnosed every year in the EU (Eur J Cancer. 2011 Oct 25). Individually, each of the 198 identified rare cancers is considered "rare" but collectively they represent about 22% of all cancer cases diagnosed annually in the EU, including rare adult solid tumours (13%) such as brain tumours, and rare haematological cancers (8%) as well as all childhood cancers (1%) including all pediatric brain tumours. For more information about Rare Cancers Europe, visit http://www.rarecancerseurope.org/ ■

A landmark year for brain cancer in Australia

Barrie Littlefield

Head of Engagement, Cure Brain Cancer, Australia

2017 was a landmark year for brain cancer in Australia. It saw the launch of the Australian Brain Cancer Mission, which was closely followed by a report from the Senate Select Committee into Research for Low Survival Cancers (with a strong focus on brain cancer). The report contained 25 recommendations to better meet the needs of brain cancer patients, families and carers. This propelled Australia to the forefront of global action against this appalling disease, at a time when many other exciting initiatives were already taking place around the world.

Above: Greg Hunt (Minister for Health, left), Michelle Stewart (CEO, Cure Brain Cancer Foundation, centre) and Andrew Forest (Eliminate Cancer Initiative, right) at the launch of the Australian Brain Cancer Mission in October 2017

The Australian Brain Cancer Mission - a ten-year plan to double survival

The Australian Brain Cancer Mission (ABCM) was catalysed by Cure Brain Cancer Foundation's advocacy and awareness work over the last four years. This was amplified through participation in numerous Government submissions, as well as the Foundation's 'one message' campaign, which gave the brain cancer community a unified voice and leveraged efforts to dramatically increase awareness. These two initiatives, in conjunction with a strong focus on relationship-building, set the scene for increased research and more coordinated and targeted action, both locally and globally.

The ABCM is an AUD $100 million, ten-year plan to double survival. The Australian Government will contribute AUD $50 million through its Medical Research Future Fund (MRFF), together with AUD $20 million from Cure Brain Cancer Foundation, and AUD $10 million from Minderoo Foundation's Eliminate Cancer Initiative (ECI). The remainder will come from other contributors over the coming years. This is in large part a response to Cure Brain Cancer Foundation's long-standing call for greater focus and funding for brain cancer and its recent plea for people living with brain cancer to have 'an equal chance to survive'.

The ABCM's mission, to double survival by 2027, along with the 25 recommendations from the Senate Select Committee, provide a framework for the community and Government to move forward and address the many issues facing people impacted by brain cancer.

Michelle Stewart, CEO of Cure Brain Cancer Foundation said, "We are delighted that the Australian Brain Cancer Mission has adopted a similar mission to ours – a defined, timelined metric to increase brain cancer survival. We will continue to push to accelerate more effective treatments for patients through global initiatives such as GBM AGILE (for adults), and Biomede and the Zero Childhood Cancer Program (for children). The focus now is firmly on survival and the clock is ticking. We hope more countries and regions adopt similar initiatives, and we will continue our collaborative efforts to ensure international groups work better together, reduce duplication and competition, and quickly get the outcome we all so desperately want and need." ■

Progress in the United Kingdom heralds new hope for brain tumour patients

Recent months have seen a transformative time for brain tumour patients and their families in the United Kingdom, with pledges of significant increased funding for research, greater public awareness of the disease and a range of new projects. Here is a brief introduction to some of these.

Above: Lord O'Shaughnessy speaking at Brain Tumour Research's Parliamentary reception in Speaker's House about the work of the UK's Department of Health brain tumour "Task and Finish" group.

The "Task and Finish" report

A landmark "Task and Finish" report into brain tumours published by a UK Government Department of Health and Social Care working group has called for greater innovation in brain tumour research.

The review, published earlier this year, recognised that dedicated brain tumour research centres are an effective way of expanding and developing research capacity and capability and that appropriate drugs, originally developed for other conditions, but with potential for the effective treatment of brain tumours, should be 'repurposed' where the evidence supports it. The review also appealed to the UK brain tumour and neurosciences communities to work together to explore opportunities for research collaborations.

The report coincided with news that Baroness Tessa Jowell, a former Government Minister, was diagnosed with a glioblastoma (GBM). Baroness Jowell, in a moving address to the UK Parliament, sounded a clarion call for access to adaptive clinical trials. Baroness Jowell was present at the first UK Brain Cancer Initiative round table which was chaired by Health Minister Lord O'Shaughnessy who said: "We must all work closely together in the coming months and years to build on the issues surrounding this devastating illness, so we can see improved survival rates and a greater quality of life for those living with brain cancer."

Funding commitments bring new hope

In February there was a Cancer Research UK announcement of £25 million funding over five years and the UK Government announced that an estimated £20 million in funding would be invested through the National Institute for Health Research (NIHR) over the same time period. When, in May, Tessa Jowell sadly died, the Government confirmed plans to double its investment in brain cancer research with a £40 million 'Dame Tessa Jowell Brain Cancer Research Mission', meaning a total research package of £65 million in what the Health and Social Care Secretary Jeremy Hunt called a bid to deliver a "step change" in survival rates. The Cancer Research UK investment includes support for two new specialised centres - The Children's Brain Tumour Centre of Excellence at the University of Cambridge and a further Centre at The Institute of Cancer Research, London.

Eliminate Cancer Initiative (ECI)

During Spring 2018 the Eliminate Cancer Initiative (ECI) - already known in Australia and the US - held the first meeting of a steering group in London to meet leaders of the UK brain tumour patient and caregiver community and discuss collaborative projects which could benefit from ECI's expertise and funding support.

The social and financial impact of brain tumours

Additionally, the All Party Parliamentary Group on Brain Tumours (APPGBT) launched an Inquiry into the social impact and cost of brain tumours. Submissions have been gathered through a web forum and the Inquiry is expected to report its findings in Autumn 2018.

Sue Farrington Smith MBE, Chief Executive of Brain Tumour Research, reflected on an extraordinary period for brain tumour campaigners: "No one doubts that there is much more that needs to be done but progress is being made and 2018 is proving to be a landmark year on our journey to a cure. Like patients and their families across the UK, I am impatient for change and pleased to see that the momentum for this is now growing." ■

News from the UK National Cancer Research Institute (NCRI) Brain and CNS Tumours Supportive and Palliative Care Subgroup (S&PC)

Dr Helen Bulbeck

brainstrust and NCRI S&PC Group Secretariat

This brain and CNS tumours subgroup, which sits within the National Cancer Research Institute, is driving the supportive and palliative care clinical agenda for people living with a brain tumour in the United Kingdom. Its raison d'etre? To improve quality of life and outcomes for patients and caregivers living with a brain tumour.

Our long-term aims are:

- quality trials and studies in neuro-oncology: develop a system to improve the number and quality of clinical trials in supportive and palliative care
- grantsmanship in neuro-oncology: support grant submissions fulfilling NCRI brain S&PC criteria in priority areas for clinical research
- build relationships in neuro-oncology: with governmental, professional, clinical and patient public involvement (PPI) communities
- increase patient/caregiver opportunity for involvement in clinical studies in supportive and palliative care and quality of life.

Here's a taste of what the group has been working on:

NOCTURN (Neuro-Oncology Clinical Trials UK Research Network)

The NOCTURN website developed out of the James Lind Alliance (JLA) Priority Setting Partnership (PSP) in Neuro-Oncology website. Its purpose is twofold:

1. to act as a resource for neuro-oncology clinical researchers to obtain all the latest funding sources and resources that assist application for clinical research funding
2. to inform the community about the Top 10 JLA questions and the help that NCRI brain CSG can give. The JLA questions represent the top ten treatment uncertainties in diagnosis and management of primary central nervous system tumours and were suggested and voted on by a wide range of stakeholders including brain tumour patients and caregivers.

NOCTURN is community-led and is a place where caregivers, patients and healthcare professionals can come together to discuss various neuro-oncology topics, such as the JLA PSP and top ten priorities, research and funding. The site invites engagement through discussion threads – anyone can join in.

BT-LIFE

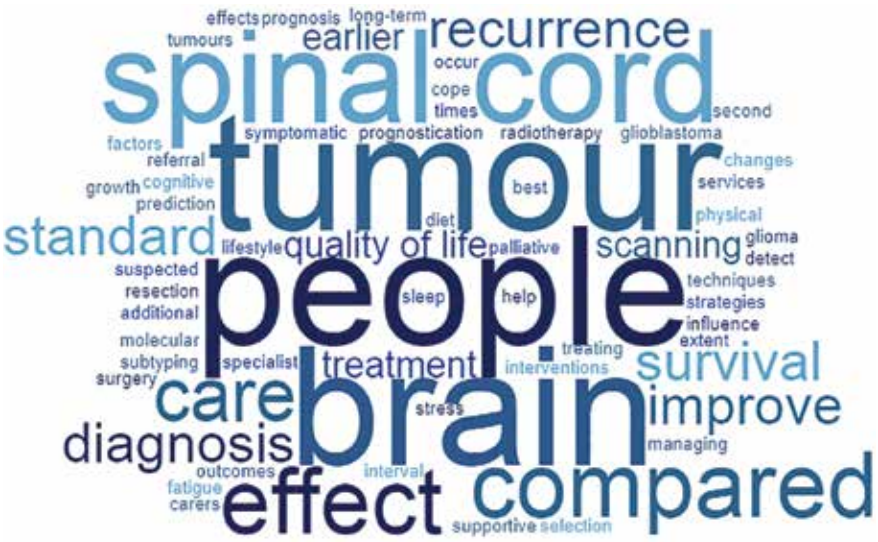
Fatigue is highly prevalent among patients with a primary brain tumour (PBT), with reports of fatigue ranging between 40-70%. As well as being extremely common, fatigue can also markedly reduce quality of life. However, to date little research has been directed toward non-drug interventions for fatigue in patients with PBT.

BT-LIFE is a multi-centre randomised controlled trial (RCT) aimed at addressing the feasibility of implementing two forms of non-drug intervention in adults with fatigue and PBT. It is a three-arm trial.

Above: Dr Robin Grant (Edinburgh, Scotland) head ups the UK NCRI Brain and CNS Tumours Supportive and Palliative Care Subgroup

Participants in the first arm will receive a ten-week programme of personally-tailored health coaching, working on small patient-centred goals surrounding their lifestyle. Those in the second arm will receive an additional 'patient activation' coaching intervention aimed at boosting their knowledge and skills to manage health coaching. The third arm is a control arm in which patients will receive standard care. The research team will assess the feasibility of implementing these non-drug interventions in fatigued PBT patients.

The study is on-track to open by May 2018. Acceptable completion, together with patient views raised in a parallel qualitative interview sub-study, will guide a full future randomised control trial of non-drug interventions for fatigue in PBT.



JLA Incubator Day: Does earlier diagnosis of patients with brain tumours improve outcomes?

This is one of the JLA top ten questions for clinical research in neuro-oncology. Some symptoms are quick (e.g. progressive focal unilateral weakness, dysphasia/confusion) while others are slow (headache +/- personality or cognitive or memory changes).

Incubator days are structured, interactive workshops, which bring together the best researchers (chief investigator and content experts), research study methodologists and clinical trials units staff (trial management, protocol development expertise, statisticians, data management), in order to drive trial development in a particular area. The overall aim of these meetings is to produce the highest quality research trials proposals and direct them to the most appropriate funders.

In an incubator day held in December 2017, primary care specialists, neurologists, and researchers interested in the area met to discuss potential proposals for clinical research.

A potential randomised study of patients with "headache suspicious of cancer" to different pathways to care (direct access to imaging versus referral to a neurologist) with clinical and health economic endpoints was discussed but it was considered too early for such a study and the clinical endpoints need to be better considered. However, a prospective multi-centre study of "headache suspicious of cancer" looking at the red flag features in the history, the value of a simple fast screening test of cognition (semantic verbal fluency test) and other features prior to imaging, will be developed.

Further work is planned studying the value of integrating optometry into the General Practitioner referral pathway where the GP is uncertain whether or not there is papilloedema or visual field defect.

SPRING (Seizure PRophylaxis IN Glioma)

This UK National Institute for Health Research (NIHR) health technology assessment (HTA) funded study, due to start this year, will see over 800 patients with brain tumours, who do not have epilepsy, randomized to either prophylactic levetiracetam or to no anti-epileptic drug (AED) prior to first brain surgery. This will be the first randomized controlled trial examining the potential seizure reduction benefits, or harms, of the newer generation AED most commonly prescribed in brain tumour patients.

It is the largest RCT examining prophylactic AED and is a collaboration between neurosurgeons, neurologists, oncologists, health economists and a cancer trials unit in a supportive care RCT.

Get Data Out: New, routinely accessible brain tumour data to help people understand the impact of the disease

brainstrust and Public Health England have been working on a project which will see the regular release of new brain tumour data. This data will help us all to understand the impact of brain tumours at a population level. There will be regular publication of anonymised data on:

- brain tumour Incidence
- survival
- brain tumour treatment
- routes to diagnosis

This is the vanguard to a wider piece of work to establish ways of producing anonymised data on rarer cancers. With the systems now established, and patient anonymity guaranteed, the stage is set for unprecedented access to data on rarer cancers.

This initial release of data marks a watershed as Public Health England is able to ensure that safe and secure policies, processes and procedures are in place which meet the requirements of the law and best practice to ensure that patient data is shared in a way that does not compromise anonymity.

However, data on its own does not tell a story. We (brainstrust and the NCRI Supportive and Palliative Care sub group) will be working to bring meaningful narrative to this data, with the support of clinical, patient and public health partners in the coming weeks, months and years. We will also be working to make the data visually engaging, accessible and meaningful to the general public.

Early analysis of this data bears some significant headlines for our community around survival rates in non-malignant brain tumours, routes to diagnosis, radiotherapy data and variable outcomes for groups of patients who receive the same treatment. For more information please visit www.brainstrust.org.uk. ■

Men Who Cry

Joerg Haenicke
Bergen, Norway

JOERG Haenicke had everything he could have wished for. A wife, a dog, a good job and a comfortable flat in his adopted hometown of Bergen, Norway. But at age 36, his world was turned upside down when he was diagnosed with a glioblastoma. As he came to grips with his new life of hospital visits, MRIs and battling severe fatigue, he decided to write a book about his experience.

Brain cancer. Cancer in the brain. We might not be able to state that one type of cancer is worse than any other, but a brain tumour doesn't only threaten our health, it threatens the way we think, the way we act, the way we function in our day-to-day life.

I was diagnosed with a grade IV brain tumour, or glioblastoma (GBM), in March 2014. An emergency surgery was followed by hospital, radiation and several months of chemotherapy. In the beginning of 2015, I was struck with severe fatigue and exhaustion as a result of the treatment I had been given to prolong my life after surgery. It had me literally walking on all fours for several months, before I managed to push back.

> "It was so terrible not to be able to actively live. To lack the ability and motivation to get up and contribute. One of the worst moments was when I went shopping. All the people in the store, the colours, the smells, and the flickering lights in one of the fridges, became too much for me. I kneeled down hoping someone would find me and take me away from there."

Upon finding brain cancer and fatigue-related groups on social media, I realised that not only was I not alone with my challenges, but that there were thousands of people out there with brain tumours - struggling, fighting, surviving...

Early on, while in hospital, I had made a conscious decision that I didn't want to stand on the sidelines when it came to my fight against cancer. Now I realised that I didn't want to stand on the sidelines in the fight against cancer, period.

One thing I saw immediately, was that in those online groups women were a lot more vocal then men. Statistically, over half of newly diagnosed cancer patients are men. Where were they? I experienced a wide range of emotions during this time, and seeing that so few men voiced the same worries and fears that I experienced, I came to the conclusion that maybe the men didn't know how to speak out.

The idea was born to write a book about my time in the hospital, and the months that followed, as a kind of self-aid book for men. Of course, it would also help me remember what had happened and act as a kind of therapy. But the plan to share it with anyone interested or anyone who might gain a benefit from reading it was there from the start. It would be an honest tale of a man, diagnosed with

terminal brain cancer, to inform, to inspire and to give words to my fellow men in this struggle.

I considered how a book for men should be, and the answer was: short. I don't know a lot of men who enjoy reading books, and even fewer who would touch a self-aid book with a 10-foot pole. So I tried to write my story as I would have written a manual. Short and to the point.

I decided on the themes that I found were most important, like talking about fear, and the transition from surviving to living. How I dealt with fatigue and energy-balancing on a daily basis. The advantage of keeping the book short and to the point was of course the chance that guys actually could be persuaded to read it. Also it would give me the chance to go into these thematics deeper at a later point, and find more precise words that I believe were needed to express the horror that had entered our lives.

"The last fear was that I was afraid to die, and that took some time to master. We look at death from a distance. Everyone knows very well that life ends in death, but mostly we study the topic through a window which gives us enough distance to feel safe."

Words and pictures delivered with an honest vulnerability are a powerful tool that can be used to inspire in a way a scientific article might not. The surgeon told me that I could choose to work, but finding joy in life mattered most with a diagnosis as severe as a GBM. Being diagnosed with this disease showed me something I had struggled my whole life with. It showed me what I wanted to do with this life of mine, my calling if you will.

I wanted to help people who struggled, to have more of a life whilst dealing with this disease. Because it gave what had happened to me a certain kind of meaning, it made it easier for me to accept the diagnosis. "Men Who Cry" gave me the confidence to sit down and hammer out my ideas, my words and my dreams into sentences. I could publish those in online cancer forums to inspire other patients and caregivers to live, instead of merely surviving. Going on a quest to search for the mental pictures, expressions and photos that they should hear, see, or might want to say, became my work.

I believe that the meaning of life, is living.
Not just getting out of bed, breathing in and out,
hurrying from one must-do to the next have-to-do.
Never resting, never appreciating the stillness
of the moment. Constantly being annoyed by the
little things, the trivial things, the meaningless things.
Living is a concious look to the horizon. A deep breath.
Enjoying the powerful wave of awe that can hit you when
listening to a wonderful melody, sung by a beautiful voice.
The feeling of love, that can overwhelm you, when meeting
a dear friend again, after years apart.
Living is a grand experience, It takes practice.
Patience. An open mind and a loving spirit.
And more than that, it takes a conscious decision
to want to live. At first it's demanding; in the beginning
it's difficult. But once you get the hang of it...
you can pack a months worth of ordinary life into a new day.
And it's an amazing experience, living this thing we call life.

Joerg Haenicke

I found that living is, or should be, a conscious decision. Even though I had setbacks, failings and was knocked down by life several times, I made a habit out of getting up again, sharing my ups and downs with the brain tumour society to show that bad days are a part of this journey, as well as good days, and should be valued. There is no shame in crying (and comfort-eating chocolate and having a cold beer) on a bad day and there is no greater joy then a celebratory dance after a clear scan.

It is my conviction, that the story of a brain cancer patient often will be looked at, as will my book, as being short and intense. But I believe it could also be viewed in a different manner: full of life. ■

Man to Man - Tips for Men Dealing with a Brain Tumour

1. We guys often pride ourselves on being responsible for those around us and being in control of our lives. Who we are is a result of the choices we made. However, we have to remember that none of the choices we made has led to this cancer. At the end of the day we were just unlucky. No point in wasting time and energy on a guilty conscience.

2. An often seen trait among men, when faced with the dire statistics for a brain tumour, is to put on a brave face and accept their fate. But it is important to remember that we are not a statistic. Especially to those who care about us. We have to write our own cancer story.

3. Use your psychologist, therapist and other professional help available to you. To me it felt odd contacting a psychologist at first. I didn't feel I would need one to be honest. I knew all there was to know. I read the notes. But it's not all about us, the patient. It's about those who care about us too. And they need to see that we are getting all the help we can.

4. Occasionally, when meeting with my oncologist, I went there with some questions. In the beginning I didn't write them down because I felt like a schoolboy with a note, sitting in front of the principal. The result was, that I often forgot a question or two and had to call back. So now I take notes and even ask if I can record the conversation. That way I'm certain that I get all the information I need.

5. Following the stereotypical male role model is demanding, especially when coping with fatigue. Fatigue is among the most common side effects after chemotherapy. Especially for the man who used to "do it all", fatigue can pose a big challenge. Being exhausted, both physically and mentally, can bring even the strongest to their knees. Remember that this exhaustion is not purely physical. Following up on mental challenges is equally important.

6. We don't always realise how much energy it costs our loved ones to support us in our fight. It is therefore crucial that we seek out and accept support from friends and family so our loved ones don't burn themselves out. We have to swallow our male pride on occasion and ask for and accept help. Learn to say these important three words and use them without shame: "I need help!"

7. Challenges with reproduction are not something all men are comfortable talking about. So some thematics are quickly ignored when conversing with an oncologist. But it is worth knowing that sperm quality can get damaged during treatment. So if you plan on fathering a child during or after treatment, check with a doctor. Freeze some of your swimmers before therapy starts.

8. For me it was demanding to show those around me what the challenges in my life were with my illness. Finding peer groups, where I didn't feel like I needed to pretend, and where I could experience a feeling of normality with my condition, helped me a lot.

Joerg Haenicke's book, "Men Who Cry", is available online at: http://bit.ly/2nq0uls

The Dragon Master Foundation - Helping Make Braver Choices in the World of Brain Tumor Research

Amanda Haddock

President, Dragon Master Foundation, United States

Dragon Master Foundation was founded in 2013 in memory of my son, David Pearson, a teenager who almost always thought of others before himself. When he was diagnosed with cancer, he was more concerned about the other kids, even though his diagnosis was terminal. He was always looking for ways to make everyone's day brighter, and he was such a big proponent of cutting-edge research. He participated in clinical trials, not for himself, but to further science. Whenever a trial was proposed to David, he would always ask if it would help others. If they said "yes", then so did he. He never asked about how long it would take or if it would be painful. He just wanted to help.

Despite all the trials and the positive outlook, medical science couldn't save David. When he passed away, we knew that he expected us to continue trying to find cures to save other people. His voice is always with us, encouraging us to keep going.

David provided the drive, but a comment from Dr. Anna Barker, former U.S. National Cancer Institute Deputy Director, provided the direction. Dr. Barker shared the need to compare cancer research records on a very large scale. When it became apparent that this was not really a focus for most institutions, we knew this was the piece we should work on. Our vision was to have everything a researcher could need all in one place. A sort of "Google" for cancer research.

We wanted to create a place where you could see a patient's clinical records, their genome, and their tissue samples together and cross-references. We also wanted it to include multiple types of cancer and/or disease, as well as healthy people for comparison. We also wanted that data to

Above: Amanda Haddock

be available not only to researchers, but to patients and their families who are eager to help find cures. We wanted to compare adult and pediatric data, and we wanted it all done in real time. We knew the technology existed to make it so, but the funding and the collaboration needed were daunting.

At the time, most people thought we were crazy, but David's neuro-oncologist at Children's National Health System in Washington, D.C., Dr. Eugene Hwang, agreed to help us forge ahead with the plan. He connected us with researchers at Children's Hospital of Philadelphia and the Children's Brain Tumor Tissue Consortium (CBTTC). We discovered a whole group of people who shared our optimistic vision. In fact, they had already begun working on the structure for the research platform that has become known as Cavatica. It is named after the spider in the children's novel Charlotte's Web, who used collaboration and intelligent design to save the life of her friend.

We were so impressed with the CBTTC, their work, and their attitudes that we have been almost exclusively devoted to that project ever since. Countless doctors and researchers involved with the project have taken time to make sure we understand ways we can make an impact. But in particular, Dr. Adam Resnick has taken time to help us understand the technical aspects so we could really make a difference. Dr. Resnick is the Director of Data Driven Discovery in Biomedicine (D3b) at Children's Hospital of Philadelphia (CHOP), a department developed after the hospital saw the impact of his work with CBTTC.

Still in it's infancy, Cavatica launched in October 2016, to very positive reviews. Along the way, I was recognized by the White House as a Champion of Change for Precision Medicine because the work we are doing will most definitely help target specific treatments for patients. Members of our team, including myself, have participated in Cancer Moonshot meetings and Cavatica was recently picked as the infrastructure to house the NIH's Gabriella Miller Kids First Data Resource Center which will combine birth defect data and pediatric cancer data for cross-comparison.

In some ways, this project has advanced very quickly. It is an international effort with data coming in from several different countries, and being accessed by even more. Cavatica is already the largest clinically annotated pediatric cancer database on earth. It has already reduced the amount of time to request and receive bio-samples, and it has facilitated collaboration between partners who had little to no interaction prior to Cavatica's

Above: Amanda Haddock's son, David Pearson, whose brain tumour journey inspired the establishment of the Dragon Master Foundation

Above: David and Amanda

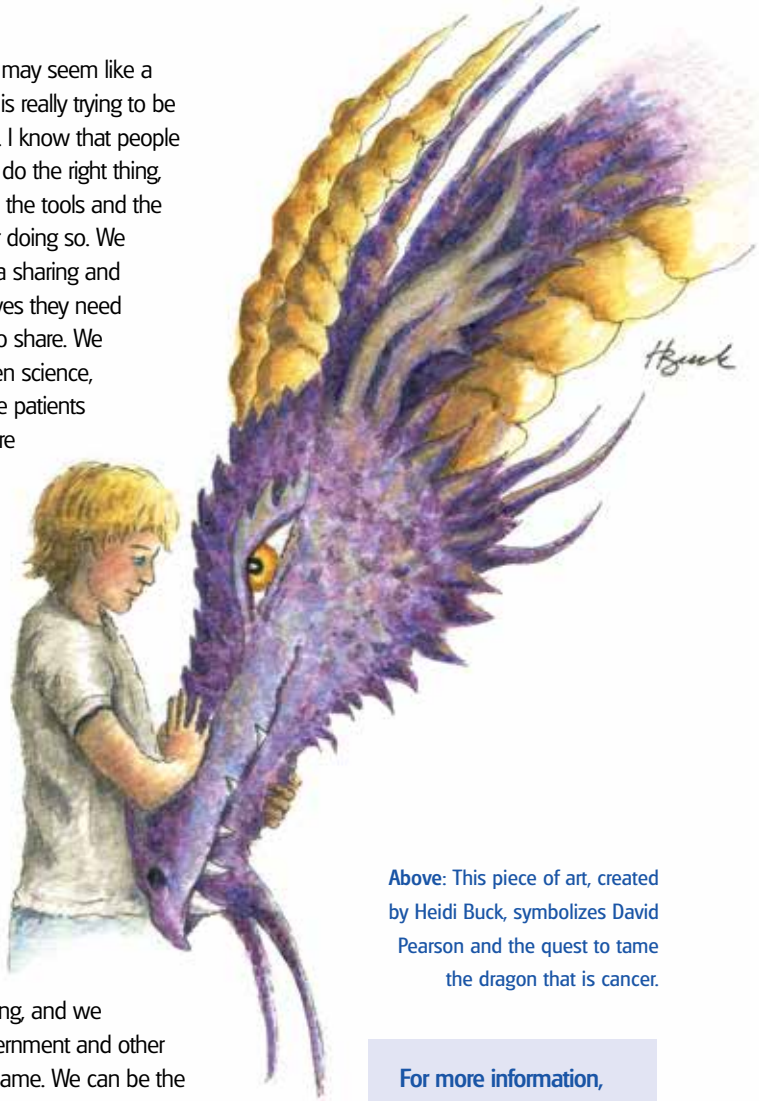
existence. I'm very proud of that, but it is such a small step forward when we look at what we ultimately want to achieve. We are in this to save lives, and every day, more people are diagnosed.

Unfortunately, the medical and academic communities are only partially onboard with the idea of rapidly sharing data because - in my own view - the existing systems are set up in a way that reward people for being the first to make and publish a discovery. The consequence of such a protective approach is the fear that if they share data they collect before publishing the final outcome, they could open themselves up to the possibility that someone else might make an important discovery before they do, aided by the information made available at an interim stage.

I've observed that if you ask a patient or their family, they will tell you they don't care who makes the discovery, as long as someone makes it fast! However, if you ask a hospital board of directors or a funding institution, I believe that it is quite possible that they would say that they want the discoveries to be made at their facility or from the work they are funding. In the business of cancer research, there is no room to fail. I fear that, to some degree, we've gotten away from the basic scientific principles and the core medical directives in support of a system that can put careers over cures, profit over patients.

I know my opinion may seem like a harsh indictment, but it is really trying to be more of a wake-up call. I know that people doing research want to do the right thing, but we must give them the tools and the reward mechanisms for doing so. We need to encourage data sharing and give people the incentives they need to survive when they do share. We need to empower citizen science, even though it may give patients more power than we are comfortable with. In short, we need to shake up the system and the status quo, in order to make braver choices in regards to research.

For our part, we will continue to fund open access research and the infrastructure to support it. We will continue to speak up for those who are trying to do the right thing, and we will encourage the government and other foundations to do the same. We can be the generation to improve this system and speed the path to cures. We just have to be brave enough to endure the change. ■



Above: This piece of art, created by Heidi Buck, symbolizes David Pearson and the quest to tame the dragon that is cancer.

For more information, see https://www.dragonmasterfoundation.org

Peace of Mind Foundation's Women's Retreat - Showcasing the Importance of Connection, Respite and Support

Bec Picone

Founder/Director, Peace of Mind Foundation, Australia

In October 2017, Australia's Peace of Mind Foundation hosted their 2nd annual Women's Retreat for Brain Cancer in Torquay, Victoria. 60 women (patients and/or caregivers) came from all across Australia for this exclusive weekend of pampering, friendship and indulgence. The women stayed at the 4.5 star Peppers The Sands Resort, the perfect setting for new friendships to form and much fun to be had.

Peace of Mind Foundation was founded in 2013 by Bec Picone and Clint Matthews, brother and sister, after Clint lost his wife Caroline to brain cancer in 2011. The organisation runs a brain tumour support group, offers funded counselling and financial aid for affected families and a small range of in-home services to help alleviate day to day stresses. Nevertheless, Peace of Mind Foundation has become most well-known for its social days and incredible retreat weekends for families and women which it runs every year.

Above: Peace of Mind Directors and guest speakers including humanitarian Moira Kelly AO (far left) and Australian Paralympian and rare cancer survivor Kelly Cartwright OAM (centre). Credit: Louisa Jones photography

Isolated no longer

Founder/Director, Bec Picone made the decision to start running these retreats after recognising the isolation that a brain cancer diagnosis can have on families. Brain cancer is a rare disease and Australia is such a widespread country geographically that many patients/caregivers may never get the opportunity to meet others on the brain cancer journey. Launching an annual event that brings brain cancer-affected families together is a way of helping support families in their greatest time of need and help bridge that gap within the brain cancer community.

Women's Retreat 2017 was a wonderful showcase for the importance of connection and the need for support and respite. Sixty women, all strangers or 'Facebook' acquaintances, came together and met for the first time. They all clicked. There is something extremely powerful about bringing together women who have all shared the common experience of brain cancer. The women forged close ties with one another very quickly. Most importantly many laughed, relaxed and had fun for the first time in a long time!

Above: They could have danced all night! Participants enjoying the Women's Retreat in Torquay, Victoria, Australia. Credit: Louisa Jones Photography

The retreat programme

On the Friday evening of retreat, after the women excitedly had finished opening their free gift bags, the local Rotary Club volunteered their time to come to picturesque Torquay Beach and cook a barbecue dinner for everyone. This was a great, relaxed setting to start to converse and get to know one another, including all of the wonderful volunteers that were helping out that weekend. The event is managed by Bec Picone but it is largely a wonderful collaboration of support from local businesses and individuals all donating their time, services and products that truly makes it work. Peace of Mind runs these events on an extremely small budget but manages to raise over AUD $80,000 of in-kind support to help make these retreats possible each year.

The favourite day of retreat is always the Saturday. On the Saturday all the women were welcomed into the 'pop up' pamper room - a floor to ceiling glass walled room

Above: Pamper sessions included manicures, massages, facials, hair-styling and other treats. Credit: Louisa Jones Photography

Above: Retreat guests and volunteers. Credit: Laura Scholfield Photography

Above: Volunteers provide a smiling welcome to women participating in the Peace of Mind Foundation's Women's Retreat. Credit: Louisa Jones Photography

Above: Thirty classic and muscle cars passed by the famous Aireys Inlet Lighthouse. Credit: Laura Scholfield Photography

that overlooks the stunning 'The Sands' golf course. While in the pamper room the women enjoyed a selection of pampering activities run by over 30 volunteer professionals: massage, reflexology, facials, nails, spray tanning, hair styling and make-up. The women were glammed-up in preparation for the Saturday night cocktail party and guest speakers.

The guest speakers are a real highlight of the weekend and always leave a lasting impression with the guests. This retreat welcomed the very inspiring Moira Kelly AO – International Humanitarian and Global Peace Maker. Another guest speaker was Australian Paralympian and rare cancer survivor, Kelly Cartwright OAM. Both of these women have personal life stories which inspired hope, passion and perseverance in the women at the retreat. And a few of the women were a little star struck too!

On Sunday, the final day of retreat, Peace of Mind surprised the women with a selection of over 30 classic/muscle cars to take for a cruise down Australia's famous 'Great Ocean Road'. A local car club kindly recruited its members and they made a day of it in support of helping these women affected by brain cancer. The weather was perfect for a lazy Sunday drive to Bells Beach Lookout, Aireys Inlet Lighthouse and then lunch at the Great Ocean Road Chocolate Factory. Yummy! The women all posed for a group photo and then it was sadly time to conclude the weekend and get the women safely back to their homes.

In April 2018, Peace of Mind hosted its 2nd Family Retreat for Brain Cancer and approximately 100 people of all ages joined them for a weekend of adventure, fun and friendship. October will be time again for Women's Retreat 2018.

Peace of Mind aims to find more financial sponsors in 2018. We look forward to increasing our reach within the brain cancer community and providing hundreds more families with the opportunity to be part of these memorable retreats where participants will make new friends and share experiences.

As we all know, the brain cancer journey is challenging and life changing, so having people nearby who truly understand is a real blessing. ■

For more information about the work of the Peace of Mind Foundation, please visit http://www.peaceofmindfoundation.org.au/

Kenya - International Brain Tumour Awareness Week 2017

OUR colleagues at the Brain, Spine & Rehabilitation Hospital (BSR) in Nairobi, Kenya took part in the International Brain Tumour Awareness Week from 21 – 28 October 2017. They wrote: "We had TV interviews on both KBC AND K24 (two of our most popular local television channels). One of our brain tumor warriors gave an inspirational account of her determination to become a doctor despite many odds. This was a moving account of what patients go through and the power of positivity. We gave talks on the whole spectrum of care for patients with brain tumors ranging from counseling and surgery to after-care. There were also subsidized consultations for outpatients and educational material was uploaded on our social media pages.

"The TV interviews can be watched here: https://youtu.be/pIVHrTb9j4k and here: https://youtu.be/o02QvYWggWs Our social media page links are: https://www.facebook.com/BSRHospitalKenya/?ref=bookmarks Facebook. https://twitter.com/BsrHospital Instagram." ■

SUU Blundell from the walking Acoustic Neuroma Warriors reports that "this is our Facebook group's 2nd year of Walking Around the World for Brain Tumour Awareness. We have now walked around the world twice! I'm absolutely amazed at how this group has grown and how many original walkers are still with us. The average steps per person have gone from 6,000 to 7,300 per day and that's showing us that we're helping each other to take our minds off the lumps that we have/had in our heads. The more steps recorded, the more people take notice when we 'share' the final tally each week. We also send certificates to walkers each week. Our Facebook page is: https://m.Facebook.Com/groups/287356665034136 Here's me in my walk around the world shirt." ■

If you would like to donate to the IBTA…

We don't wish to receive any funds from organisations who support the "Walk Around the World for Brain Tumours" and the "International Brain Tumour Awareness Week" because it is crucial that these are directed to local, national and regional brain tumour support or research organisations in your own country.

However we do need some funding for our work and our publications.

So we welcome offers of funding from companies and philanthropic organisations and have a detailed sponsorship policy on our website that covers this subject. Enquiries should be directed to: kathy@theibta.org

If they wish to do so, individuals can also make donations directly to the IBTA via the on-line facility on our website www.theibta.org but please do not neglect your local or national brain tumour support groups.

Brain Tumor Advocacy in Japan

A look at the Pediatric Brain Tumor Network of Japan (PBTN) and the Japan Brain Tumor Alliance (JBTA)

Yuko Moue, Pediatric Brain Tumor Network, Japan
Laureline Gatellier, Japan Brain Tumor Alliance

Japan's health-insurance system covers all citizens. However, despite the numerous hospitals in Japan, information as well as the number of expert physicians are still limited, in particular for rare disease patients. Therefore, patients with rare diseases, such as brain tumors, face significant difficulties in finding hospitals which are centres of expertise for their disease.

In 2007, the Cancer Control Act was established and mainly focussed on the five major cancers in Japan: lung, breast, prostate, colon and stomach. There was no strategy concerning rare cancers.

A new era started in 2017 in Japan, when the government started promoting the registration of all cancers (including rare cancers) and targeted medical treatment as part of its national strategy, after realizing that Japan needed to keep up with the rest of the world in this aspect. This new era shows a clear shift to personalized healthcare.

Aligned activities of JBTA and PBTN in this new era

Even though the Japanese government officially declared a new era, the start has been slower for rare cancers such as pediatric and adult brain tumors. Both PBTN and JBTA are taking aligned steps and actions to avoid any delay in comparison to the major cancers.

In 2009, 44 pediatric cancer patient groups, including PBTN, came together and submitted a petition to the Japanese government. As a result, pediatric cancer core hospitals have been designated since 2012, taking as a reference point the British core pediatric cancer hospitals.

Above: Pediatric Brain Tumor Network of Japan Camp, June 2017

New pediatric clinical trials started to be implemented as well as specialized treatment and care.

In 2017, PBTN and JBTA actively contributed to the creation of Rare Cancers Japan (RCJ), and are currently members of the board of RCJ, together with leaders from other rare cancer associations such as pancreatic cancer, sarcoma, GIST, retinoblastoma, melanoma, testicular cancer and cancer of the thymus.

In addition, both PBTN and JBTA are taking a range of approaches to push forward better care of patients and improve quality of life (QoL).

PBTN-specific activities

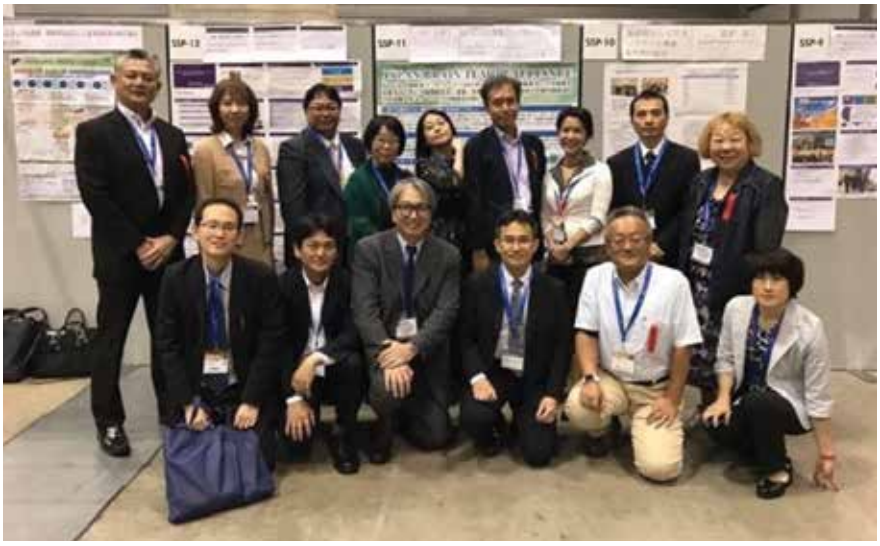
PBTN and its main collaborative group, Child Brain Tumor Parents Support Group, is a patient association for children and their families who fight brain tumors.

Since 2002, PBTN has advocated for the improvement of the medical environment, better quality of life for the families of children diagnosed with a brain tumour, improved mental healthcare and better information sharing.

PBTN's activities include seminars for patients and families and information exchange meetings with physicians, patient and parents.

Policy and government advocacy activities, including working with the ministry of health, are also a key focus of the group, which is actively involved in ongoing study groups and councils led by the Ministry of Health (including a cancer countermeasure promotion council and the study group on medical support of rare cancers).

PBTN is also actively working on creating Japan-wide family communities



Above: Japan Brain Tumor Alliance (JBTA) attendance at the Survivor Scientist program at the Japan Cancer Association meeting in September 2017

Above: Japan Brain Tumor Alliance (JBTA) General Assembly and seminar, May 2017

through an internet messaging board. PBTN also exchanges information with five other related patient groups: Cranio Park (for craniopharygioma), Miracle Brain Pediatric Brain Tumor Support Group, Japan Brain Tumour Alliance, Child Brain Stem Glioma Network and a parent group for ependymoma.

JBTA-specific activities

JBTA is nationwide network created in 2006 focusing on brain tumor patients, their caregivers and their families. JBTA supports families as they cope with all aspects of the brain tumor journey, including diagnosis, treatment, rehabilitation and care.

To achieve this support, JBTA has three main "pillars" of activity.

The first pillar is related to "support for patients and families". Information relevant to patients is available on the JBTA homepage (http://jbta.org). The JBTA website also provides a "Q&A" section accessible to any brain tumor patient or family. JBTA also distributes pamphlets to hospitals and clinics around Japan. From this year, JBTA is organizing regular brain tumour patient gatherings to increase exchanges of experience among patients.

The second pillar is to "develop patient knowledge and public awareness". JBTA organizes regular knowledge-sharing seminars with the support of specialists and health care professionals around Japan. Last year, for the first time, and as a concrete example of public awareness, JBTA organised a dedicated booth at the two-day Japan Cancer Forum.

The third pillar refers to "advocacy, networking and contribution to scientific research". JBTA actively participates in conferences, forums and symposia in Japan, for example the Forum for Japan Cancer Patients in Tokyo (January 2018), the Survivor Science Program (76th Annual Meeting of Japan Cancer Associations in Yokohama, September 2017) and abroad at the European Society for Medical Oncology (ESMO Madrid in Spain in September 2017) and the International Brain Tumour Alliance's (IBTA) World Summit of Brain Tumour Patient Advocates (London, UK, October 2017).

Future plans

PBTN and JBTA share similar issues to other rare cancers, some of which are even more prevalent in Japan than in other developed countries. For example:

1) Patients' data are not consolidated (e.g. in registries or including genomic information).
2) The number of specialists is limited.
3) Clinical trials are limited, and advanced treatment development is delayed.
4) Some medicines available abroad cannot be used in Japan.
5) The quality of life of patients and families and level of psychosocial support also lags behind other countries.

The main focus of Rare Cancers Japan is the promotion of targeted medicine, and the shift from disease-focused treatment to personalised healthcare to ensure that rare cancers (including brain tumors) are not left behind on the road to improving the situation for cancer patients in Japan.

Our concrete actions in 2018 are the following:

1) Within Rare Cancers Japan, Japan Brain Tumor Alliance and Pediatric Brain Tumor Network we are currently gathering key information through an "unmet needs survey" to highlight where a greater focus is needed to improve outcomes for patients in the upcoming months and years.
2) All of these three associations will also actively prepare and participate in the International Rare Cancers Symposium to be held on 18th October 2018 in Yokohama, Japan, which will include four main stakeholders: regulatory authorities, patient organisations, industry and academia.
3) Also, as a continuous activity, RCJ (including JBTA and PBTN) will continue to emphasize the importance of collaboration with stakeholders from Japan and abroad such as Rare Cancers Europe, Rare Diseases Europe (EURORDIS), European Society for Medical Oncology (ESMO), International Brain Tumour Alliance (IBTA), Collaborative Ependymoma Research Network (CERN), European Organisation for Research and Treatment of Cancer (EORTC) and the European Patients' Academy of Therapeutic Innovation (EUPATI) to create a brighter future for rare cancer patients. ■

My Name is Laureline and I'm a Brain Tumor Patient Advocate

Laureline Gatellier

Japan

I was diagnosed with brain cancer around two years ago, in my host country, Japan. These two years have been the most insightful ones in my whole life.

In the first year, there was fear and getting accustomed to the new status of being a "brain cancer patient" – discovering the diagnosis and coping with two awake craniotomies, radiotherapy, chemotherapy, side effects, discovering the ketogenic diet, learning about the disease by attending patient groups and conferences as an interested individual.

The second year is turning into an amazingly new, unexpected path. I became, without any intention, a "patient advocate", getting closer to my dream to actively contribute to society. All my "off" time is dedicated to patient advocacy now. By the way, I am an "almost normal" employee during my "on" time. I mean by "almost" that the constraints relate to my chemotherapy and days off used for my new "passion" as a patient advocate.

In February 2017, I presented to the Japan Brain Tumor Alliance (JBTA) information about the latest brain tumor classification by the World Health Organisation (WHO) which I learned about from my attendance at a Society for Neuro-Oncology conference in 2016 in Arizona, USA. As a result, JBTA board members invited me in May 2017 to join JBTA as a board member, to bring "new" energies to the group. One stone two birds: joining JBTA triggered another invitation, two months later, to become a board member of the new patient association, Rare Cancers Japan (RCJ), as brain tumours are rare cancers.

As a result, together with Hisato Tagawa of the Japan Brain Tumour Alliance, among others, I represented JBTA during the two-day Japan Cancer Forum event in Tokyo in August 2017. In September, I interacted with and learnt a lot from physicians, experts and advocates at the Survivor Scientist Program at the Japan Cancer Association and also at the ESMO (European Society of Medical Oncology) conference in Madrid, Spain.

Above: Laureline Gatellier (photo taken at the Japan Cancer Forum event. The Japanese Shiseido cosmetic company supports cancer patients.)

A similar experience was obtained at the Forum for the Japan Cancer Patient Program I attended in Tokyo in January 2018 where there were so many local/regional/national cancer patient associations from around the country and which are at the front line for all types of cancer patients, and with lots of questions about brain tumors and ready to collaborate with JBTA.

At the IBTA World Summit of Brain Tumour Patient Advocates in October 2017 in London, UK, I learned the latest news relating to brain tumors, and spoke with medical experts about my own treatment and compared that to treatments in areas other than my home country of Japan. I also had the opportunity to network with brain tumour patient advocates from all around the world and learn about their organisations' best practices and projects.

I also attended the American Association for Cancer Research (AACR) conference in April 2018, in Chicago, USA, as a patient advocate

One thing I learned in talking with the international physicians is that, depending on your country and on your financial resources, your access to having genetic testing of your tumour varies dramatically. Even though exciting "precision medicine" projects have started in Japan (such as the Master Key Project, consisting of genomic analysis of all enrolled patients and assignment to specific clinical trials if relevant), I myself cannot be enrolled due to lack of financial governmental support of the project. I will stay in the dark for the time being. If I am lucky, I will be accepted for genetic analysis sometime in 2019, after a change in governmental financial involvement in genetic research.

Such exposure at these meetings gave me access to basic research scientists, treating physicians, healthcare experts, patient advocate experts and leaders, as well as patient families around the world, as it gave me the opportunity to travel in Europe, the US and Japan. Trust was created with lots of new friends, all with different backgrounds and different expertise but definitely with the same philanthropic minds, with a common, and deeply rooted goal: to improve rare cancer patients' (including brain tumour patients') quality of life and contribute to saving people's lives.

The lives of amazing people are at stake - this I know as a brain tumor (and rare cancer) patient advocate myself.

There is no time to wait or waste. Let's move forward together! ■

Family Matters: Li-Fraumeni Syndrome and Inheriting the Predisposition to Multiple Cancers

By Holly Fraumeni

Li-Fraumeni Syndrome Association (LFSA), United States

Li-Fraumeni syndrome (LFS) is an inherited, genetic predisposition to a wide range of certain, often rare, cancers. Children and young adults with this syndrome are greatly susceptible to developing multiple cancers, most notably soft-tissue and bone sarcomas, breast cancer, brain and central nervous system tumors, adrenocortical carcinoma and acute leukemia. Other cancers seen in LFS patients include gastrointestinal cancers and cancers of the lung, kidney, thyroid, and skin, as well as in gonadal organs.

People living with LFS have an approximately 50% chance of developing cancer by age 40, and up to a 90% chance by age 60. Females have nearly a 100% risk of developing cancer in their lifetime due to their markedly increased risk of breast cancer. Many individuals with LFS develop two or more primary cancers over their lifetimes. In a recently published review* of data, brain cancer was the second most common cancer after breast cancer in people with LFS. The likelihood of an LFS diagnosis of children with cancers such as adenoid cystic carcinoma, choroid plexus carcinoma, rhabdomyosarcoma, and medulloblastoma is very strong. Each child born of a parent with LFS has a 50/50 chance of inheriting the mutation. Most people with LFS have inherited the mutation, but in some individuals, LFS is due to a spontaneous (de novo) genetic mutation that occurred early on in the egg or sperm cell.

LFS is caused by an inherited (germline) mutation of the TP53 tumor suppressor gene on chromosome 17. It was first recognized as a familial cancer syndrome in 1969 by Drs. Fred Li and

Above: LFS Founders Drs. Frederick Li and Joseph Fraumeni, Jr. **Photo credit**: National Cancer Institute

Joseph Fraumeni, Jr., after studying multiple early-onset cancers in children and young adults while at the National Cancer Institute, Bethesda, Maryland. In 1979, mutation of TP53 was identified in the tumor tissue of more than 50% of all cancer patients. However, it wasn't until 1990 that a germline mutation of TP53 was discovered to be the cause of LFS.

It is important to note that not everyone with a TP53 gene mutation will necessarily develop cancer, but the risks are substantially higher than in the general population. There are many known variations of malfunctioning TP53, and each can affect every person in a family differently. Most families with LFS have very high cancer rates, while others do not. Though it is challenging to estimate frequency in the general population, there are likely over 1,000 multigenerational families worldwide with LFS. However, in recent years, it has been suggested that LFS may be more common than previously thought and it is quickly being recognized as one of the most common genetic predispositions to developing early onset cancers – the third most frequent for early breast cancer after BRCA1 and BRCA2 mutations.*

A diagnosis of LFS is critically important so that affected families can seek genetic counseling, as well as screening for early detection and appropriate treatment of cancer. Research has indicated that those individuals with LFS appear to be at elevated risk for radiation-induced cancers, so the use

Image credit: Sabre Creative

of radiotherapy should be approached with caution. However, radiation therapy should not be avoided if the benefits outweigh the risks. Individuals with LFS may also be prone to the carcinogenic risks associated with certain lifestyle or environmental exposures, such as tobacco smoking or sun over-exposure. LFS patients should take preventive measures to reduce their exposures to behavioral risk factors and carcinogens.

At this time, there is no standard treatment or cure for LFS or a germline TP53 gene mutation. Numerous strategies using small molecule drugs to reactivate or modify dysfunctional TP53 protein are being actively studied, but not yet in clinical trials with LFS patients. With some exceptions, cancers in people with LFS are treated the same as for cancers in other patients, but research continues on how to best manage those cancers involved in LFS. ■

The LFSA website has a wealth of information on LFS including downloadable awareness brochures, medical resources, screening recommendations and other LFS research literature, personal and lifestyle stories, and educational materials such as webinars and presentation videos from past LFSA conferences. Please visit us at www.lfsassociation.org for more information, to donate, or to contact us.

*Amadou A, Achatz MI, Hainaut P. Revisiting tumor patterns and penetrance in germline TP53 mutation carriers: temporal phases of Li-Fraumeni. Curr Opin Oncol. 2018 Jan;30(1):23-29: 10.1097/CCO.0000000000000423. (https://www.ncbi.nlm.nih.gov/pubmed/29076966)

LFS Association

The LFS Association (LFSA), comprised of all volunteer board members from across the United States, strives to provide awareness, education, and support to the LFS community of researchers and patient families, worldwide. We work closely with the Li-Fraumeni Exploratory (LiFE) medical consortium to further research and bridge the gap to those living with LFS by providing information, enhancing access, and promoting optimal care.

Advances in research and enhanced technology have contributed to the growth and commitment of the LFSA since it was first founded in 2010. Our medical advisory board consists of some of the top LFS researchers in the world (including Dr. Fraumeni), and we have a genetic counselor advisory group to help improve lives of patient families. We are a proud member of the National Organization of Rare Disorders, and we even now have international representation with LFSA chapters in Brazil, Canada, New Zealand, Germany, Netherlands, and Saudi Arabia!

The LFSA supports research programs to include data collection, cancer research, early tumor detection, and whole-body MRI screening for children. Patient support programs include summer camp sponsorships ➤

Above: Teens at our inaugural LFSA Youth Workshop in the lab at the Huntsman Cancer Institute

Right: LFSA volunteer board member Kathleen Higgins at the US Capitol building in Washington, DC

Below: LFSA President Jenn Perry meeting up with LFSA - Brazil Chapter Chair Yasmin Shabaan for the LFS conference at the A.C. Camargo Cancer Center in Sao Paulo, Brasil

for children with cancer, emotional support for those recently diagnosed, and guidance to the best resources available. The LFSA exhibits at oncology and genetic counselor annual meetings to promote awareness, and we educate lawmakers on patient concerns at the US Capitol.

In 2017, the LFSA held their inaugural Youth Workshop in Salt Lake City, Utah, bringing together 21 teenagers with LFS from around the world for a weekend of fun and educational activities, and a lifetime of friendships. The 4th International LFS Association Symposium, hosted by the Hospital for Sick Children, and in partnership with the LiFE Consortium, was held April 25-29th, 2018, in Toronto. ■

Above: Day one (2017) of the inaugural LFSA Youth Workshop at the Hogle Zoo in Salt Lake City, Utah, USA

One Family's Story of Living with LFS

John Berkeley was first diagnosed with cancer in 1973 when he was five years old. John had taken a fall while playing outside which resulted in a bump on the back of his head. When his parents noticed a few days later that the bump had not gone down, they took him to the doctor. John was diagnosed with rhabdomyosarcoma – a rare cancer that grew at the base of his skull, within the soft tissue of the muscle.

In 1978, John's six-year old baby brother, Rob, received a bruise on his leg while playing outside that also failed to heal. Rob was diagnosed with osteosarcoma – cancer of the bone.

In the early 1990's, John's father had been diagnosed with several soft-tissue sarcomas. It was at this time that the Berkeleys - those who already had cancer - received genetic counseling and tested positive for Li-Fraumeni syndrome, the inherited, genetic predisposition to developing multiple cancers, often rare, and often early-onset.

Tragically, Rob was killed in a car accident in 2004, and John's father passed away from pancreatic cancer in 2007. Then at age 42, John was diagnosed with myofibroblastic sarcoma – yet another rare cancer of the soft-tissue.

John and his family were all treated at the Dana-Farber Cancer Institute in Boston. They were also enrolled as one of the first families followed in the long-term Li-Fraumeni Syndrome Study based at the Division of Cancer Epidemiology and Genetics, National Cancer Institute (NCI), Bethesda, Maryland. It was during John's annual whole-body MRI screening at NCI in 2016 that a mass was detected on his cerebellum. Within days, John underwent brain surgery back home in Boston, and the pathology report returned a diagnosis stage IV glioblastoma – a particularly aggressive cancer of the brain. John continues to receive treatment to keep his cancer at bay.

LFS Association

John realized early on that little information was available on Li-Fraumeni syndrome (LFS). So when the National Cancer Institute's Division of Cancer Epidemiology and Genetics offered to open the 2010 international LFS conference to patient families, John took advantage of the opportunity. It was at this workshop that the world's leading LFS researchers were able to collectively collaborate with patients, and where John first met other families living with LFS. It was here that the Li-Fraumeni Syndrome Association (LFSA) was born: patient families organized their desire to provide awareness, information, and support, worldwide, with John at the helm as the inaugural president!

Today, John continues to support the LFS Association as a volunteer board member. He is happily married to the love of his life, Lois, and is fully engaged with their beautiful (and healthy) children, fraternal twins Mallory and Zachary, aged 11. ■

The birth of the Uganda Brain Tumour Foundation

By Pastor Wilson Mugarura

Uganda

I am a brain tumour survivor, and a founder member and Vice Chairperson of the Uganda Brain Tumour Foundation (UBTUF).

I was diagnosed with a meningioma tumour on the left side of my brain in July 2014 at International Hospital Kampala (IHK), Uganda. I was then evacuated to Yashoda Hospital in India and had an operation there on 14 August 2014.

After the surgery, I returned to Uganda, but with residual side effects of the surgery such as backache and weakness of the right side of my body and pain in my right shoulder. I am currently on post-operative medication to prevent fits.

In 2016, while reading one of the local Ugandan newspapers (New Vision), I came across a similar story of another brain tumour survivor – Dr. Collins Oku. I managed to get in touch with Dr. Collins through the journalist who interviewed him and together with three other patients with similar cases, we all agreed that a foundation that would support various other brain tumour survivors should be established in our country - hence the emergence of the Uganda Brain Tumour Foundation.

Above: Pastor Wilson Mugarura

Above: Pastor Mugarura underwent a craniotomy in Yashoda Hospital in India

UBTUF now operates and collaborates alongside members of the Ugandan community including scientists, clinicians, nurses, allied health professionals, medical societies, government line ministries, pharmaceutical companies, cancer organizations, research institutes, opinion leaders, and the media in Uganda as well as patient advocacy organizations around the world. ■

For more information, contact UBTUF on: E-Mail: ubtuf2017@gmail.com / info@ubtuf.org Web: www.ubtuf.org

Walking around the world for brain tumours in Rome

The ninth edition of the Corrialmasimoperirene, a walk around the Villa Pamphili in Rome, Italy, was held last year. This 5 km walk/run was in memory of Massimo Crocco a brain tumour patient who passed away ten years ago. The event raised Euros 2700 to support the activities of IRENE Onlus which provides assistance to brain tumour patients. About 270 patients, families and friends of Massimo participated in the initiative. A cumulative total distance of almost 900 km was reached by the walkers at this event. ■

The EANO Youngsters Initiative

Alessia Pellerino, MD, Department of Neuro-Oncology, City of Health and Science University Hospital of Turin, Italy; Anna Berghoff, MD, PhD, Department of Medicine I, Comprehensive Cancer Center-CNS Tumors Unit (CCC-CNS), Medical University of Vienna, Austria; Carina Thomé, PhD German Cancer Research Center (DKFZ), Heidelberg, Germany

The European Association of Neuro-Oncology EANO Youngsters Initiative was launched in 2016 to provide a platform for networking, interaction and collaboration among young researchers involved in neuro-oncology. The aim of the EANO Youngsters is to represent the different specialties in neuro-oncology as well as the different scientific interests. The "Youngsters'" mission is to "meet, discuss, collaborate". Therefore, the EANO Youngsters committee was selected according to the different scientific interests of the members (clinicians and basic scientists) with the aim of organizing activities focused on neuro-oncological topics and enroll new members with similar interests. All members are younger than 35 years and are motivated investigators from different fields (neurologists, medical oncologists and radiotherapists, neurosurgeons, neuroradiologists, pathologists and molecular biologists) and different European countries.

Meet the EANO Youngsters

In the following lines, we want to introduce this initiative and ourselves in order to provide an overview of our mission and planned activities.

Anna Berghoff is training in medical oncology at the Medical University of Vienna, Austria. She finished the PhD program on "Clinical Neuroscience" in 2014; her main focus was on clinical and pathological prognostic factors in brain metastasis.

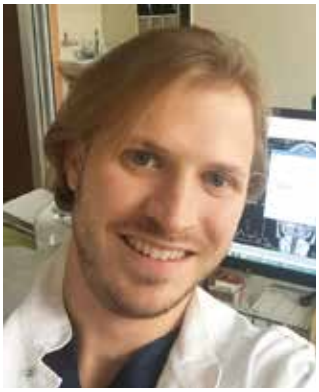
Carina Thomè is a biologist currently holding a post doctorate position at the German Cancer Research Center in Heidelberg, Germany. Her research is focused on the interaction of glioma cells with the inflammatory microenvironment.

Alessia Pellerino completed her neurology residency in 2016 and joined a PhD position at the Department of Neuroscience, University of Turin, Italy. She has a particular interest in clinical trials design with a focus on efficacy and safety of new antineoplastic and antiepileptic drugs.

Tobias Weiss is nearing completion of his residency in neurology at the University of Zurich, Switzerland. Moreover, he joined the MD-PhD program in immunology to develop a research program in immunotherapy against malignant brain tumors.

Asgeir Jakola is an Associate Professor in Neurosurgery at the Sahlgrenska University Hospital in Gothenburg, Sweden. His main clinical and research interest is quality of life in glioma patients following neurosurgical resection.

Amelie Darlix is a neuro-oncologist at the Montpellier Cancer Institute in France. She takes care of patients with both primary and secondary brain tumors, as well as cancer patients with cognitive impairment following treatments.



Aleksandar Stanimirovic is currently a resident in neurosurgery in the Department of Neuro-Oncology at the Clinical Center of Serbia. His main research interest consists of surgical approaches to midline and skull base tumors as well as minimally invasive neurosurgery.

Anastasia Vernadou is a medical oncology resident, currently working in Athens, Greece. Her special interest is in the molecular biology of gliomas. She joined an MSc program in molecular physiology to deepen her research into the biomarkers concerning brain tumors.

EANO Youngster Activities

The EANO Youngsters committee aims to address the issues of young neuro-oncology scientists within the European Association of Neuro-Oncology and is available to launch activities and provide opportunities for young scientists to meet and share new ideas. In this regard, the first networking event of the EANO Youngsters was held during the 2016 EANO conference in Mannheim, Germany and was successfully repeated during the WFNO Meeting in Zurich, Switzerland in May 2017. This networking event was well received with great enthusiasm and participation by the young attendees representing an informal possibility to exchange experience and interact with other "youngsters". The topic of discussion was how to start a scientific or an academic career in neuro-oncology, the conduct of clinical trials, basic science models and new scientific collaboration.

The EANO Youngsters committee supported the EANO Winter School in March 2018 in Athens, Greece. In particular, this event was dedicated to EANO and EAN (European Academy of Neurology) members as well as junior staff from all over Europe. The objective was to provide an update on the clinical management of common neurological complications in patients with primary and secondary brain tumors, including discussion on clinical cases from daily clinical practice.

This is only the beginning! EANO is planning an own EANO Youngsters session entitled "Perspectives in Neuro-Oncology" during the next EANO meeting in Stockholm in 2018 (see https://www.eano.eu/eano2018/home/). The program is attractive and will consist of interaction between well-known and younger speakers.
The EANO Youngsters are also active in social media and the World Federation of Neuro-Oncology Societies (WFNOS) Magazine. The EANO Youngsters have provided an interesting contribution on their personal view on mentoring. "How to find a good mentor?" or "How to get the most out of your mentoring?" are questions that young researchers ask themselves frequently as they develop their careers. The WFNOS Magazine article highlights the dreams and experiences of the members of the EANO Youngsters committee with inspiring comments from their mentors (see WFNOS Magazine 2017;Volume 3: pp 146-148 - https://www.eano.eu/fileadmin/content/News_magazine/WFNOSM_2_2017_3.pdf).

Questions and challenges

Furthermore, prior questions for EANO Youngsters in daily clinical practice are:

- "Which is the best way to communicate a diagnosis of a brain tumor to the patient and caregivers?"
- "Will the patient be a good candidate for a clinical trial?"
- "Will the family and caregivers be able to manage their feelings and support the patient during treatment?"

Many patients and relatives often feel lonely and isolated because they think that what they are experiencing is unusual, so they feel ashamed to talk about it or ask for help.

A major challenge for clinicians is the management of brain tumor-related epilepsy. Young neuro-oncologists must be able to recognize different aspects of seizures, including semeiology (symptoms or signs of disease), antiepileptic drugs and interactions with antineoplastic treatments. On the other hand, patients experience anxiety regarding new potential seizure events and are scared about the social and working consequences of epilepsy. Seizures and brain tumors may be emotionally overwhelming for patients and caregivers, thus a young neuro-oncologist must learn to face these critical situations with adequate medical knowledge and empathy.

We are all working together to establish wide programs for EANO Youngsters in the future, with new activities and networking events in line with our mission: "meet, discuss, collaborate". ■

EANO Youngsters have a Facebook page

The EANO Youngsters have opened the EANO Youngsters Facebook Group webpage in order to keep in touch with other "youngsters", exchange experience, ask for advice from the community and share information, e.g. on trials or scientific papers. We want to fill the Facebook group with more life and share interesting articles in an online journal club. Just enter "EANO Youngsters" on the Facebook platform, or write an email to Anna.berghoff@meduniwien.ac.at or C.Thome@dkfz.de and join the community!

Raise awareness of the challenges of brain tumours - plan an event for **International Brain Tumour Awareness Week 2018** (20-27 October)

Piecing it Together for Brain Tumour Awareness

Dr Anke Brüning-Richardson

Senior Research Fellow, Leeds Institute of Cancer and Pathology, University of Leeds, United Kingdom

In last year's edition of *Brain Tumour* magazine, we covered the story of the UK-based PPR Foundation, which has been supporting the work of Dr Anke Brüning-Richardson. In the article, Dr Brüning-Richardson put out a call for those around the world who were interested in brain tumour research or who were patients/caregivers/family members themselves, to send her a textile-based piece of material (20 cm X 20 cm) depicting the maker's association with/feelings about brain tumours. Here, Dr Brüning-Richardson updates us on her patchwork public engagement activity and progress on the brain tumour quilt project.

Above: Dr Anke Brüning-Richardson surrounded by some of the more than 90 squares she received from patients, caregivers, researchers and others for the "Piecing it Together" quilt.

My name is Dr Anke Brüning-Richardson and I am a senior research fellow at the University of Leeds in the UK. Currently I am investigating novel ways to target the spread of brain tumours into healthy parts of the brain.

I am honoured that my research has been funded over the past six years by a local charity, The PPR Foundation. I have always enjoyed the interaction with members of the public when talking about my research. The close collaboration with the charity instilled in me the desire to also do "my bit" outside research and I became involved in public engagement activities supported by the University of Leeds public engagement network (pepNet). This snowballed into hands-on activities for children at various science fairs, winning awards from the University for public engagement and being chosen by the Zoological Society of London to take part in Soapbox Science to promote women in science.

One of my activities led to the creation of a quilted brain ("Brian the Brain") with a detachable fabric brain tumour, which has been incredibly popular during my interactions with younger children. Brian the Brain has helped dispel misconceptions about brain tumours and has allowed a dialogue to develop between members of the public and science researchers.

For my follow-on activity, I envisaged a big and visually stunning display. Based on my previous experiences with Brian the Brain, this time I wanted to reach out on a much wider basis with active audience participation.

A chance conversation with a member of the Leeds public engagement team as well as with Kathy Oliver, the co-founder of the International Brain Tumour Alliance (IBTA), who really liked the quilted brain, made me realise that I also wanted to run an activity that has global audience participation.

"Piecing it Together" is the creation of a quilt consisting of 20x20 cm textile-based squares created and donated by members of the public. The squares depict the maker's association with brain tumour awareness, for example, their feelings or thoughts on brain tumours or brain tumour research.

Piecing all of the quilt squares together creates a whole, multi-faceted imagery which serves as a symbol of this complex disease and its research as well as reflecting individual participant diversity and experiences.

In addition, the University of Leeds is in the English county of Yorkshire and the county's history is tightly linked with the textile industry. So this piece of work also reflects the cultural heritage of Yorkshire and may thus feature in local exhibitions celebrating the county's rich textile industry.

After a call for participation in the IBTA's 2017 edition of its magazine, *Brain Tumour*, and via social media and at science fairs I was able to collect over 90 squares made by brain tumour patients, their relatives, people interested in science and children.

The squares arrived from as far away as Canada and I am absolutely amazed by the response I had. Currently I am in the process of putting all the squares together with the help of a textile lecturer at Leeds and will be able to show the end product in the next issue of the IBTA magazine.

In the meantime, I would like to thank all of you who participated in this activity which has woven together many of the varied strands of the brain tumour journey into one story of determination, courage, dedication and hope. Watch this space next year for the finished Piecing it Together quilt for brain tumour awareness! ■

Photo credit - Freya Richardson

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.

ABTA Welcomes New President and CEO Ralph DeVitto

The American Brain Tumor Association (ABTA) has recently appointed a new President and CEO, Mr Ralph DeVitto. Here he shares some of his plans and aspirations for his new role. The IBTA wishes Ralph every success!

American Brain Tumor Association®

International Brain Tumour Alliance (IBTA): What responsibilities come with your new role as President and CEO of the American Brain Tumor Association?
Ralph DeVitto (RDV): My day to day work involves two main functions; liaising with the ABTA Board and senior staff to create the organization's strategic direction, and ensuring the effectiveness, impact and efficiency of the work of the ABTA. Our organization operates under the premise of celebrating what we accomplish, while recognizing that all of our efforts in fundraising, research and patient services must be increased to most effectively meet the needs of the brain tumor community.

IBTA: What are your first impressions of the brain tumor arena?
RDV: What always strikes me about any cancer related population is the courage and determination of the patients. In my short time in this arena I have been moved by the journeys of patients and caregivers facing a variety of brain tumor battles. What I find most staggering is how much faster than other forms of cancer the time from diagnosis to making a treatment decision can be. Most heartbreaking of all are the stories from patients who admit, if they had access to the full slate of information, they likely would have made a different treatment decision. Those stories are why I believe the amount of research and overall attention to this area is not adequate, and why I want to work in collaboration with both domestic and international partners to bring about more government and private resources going to this fight.

Above: Ralph DeVitto, the new President and CEO of the American Brain Tumor Association (ABTA)

IBTA: What led you to become involved in this field?
RDV: In a previous career life I spent a good amount of time in the public policy world. A little over twenty years ago I received an offer to use my public policy experience to help shape initiatives as the first Vice President for Government Relations with the Florida Division of the American Cancer Society (ACS). In my time in that role, I was involved in collaborative and successful efforts to make significant public policy and funding changes in a variety of tobacco and breast cancer issues. The more time I spent with patients, caregivers, researchers, and donors in that community, the more I was determined to try to make an impact. I served in a variety of executive roles with the ACS, all of which were very fulfilling. I was approached to consider applying for the President and CEO role of the American Brain Tumor Association and the more I learned about the organization - and especially my time with the Board members of the ABTA - I was certain this was an opportunity I should accept.

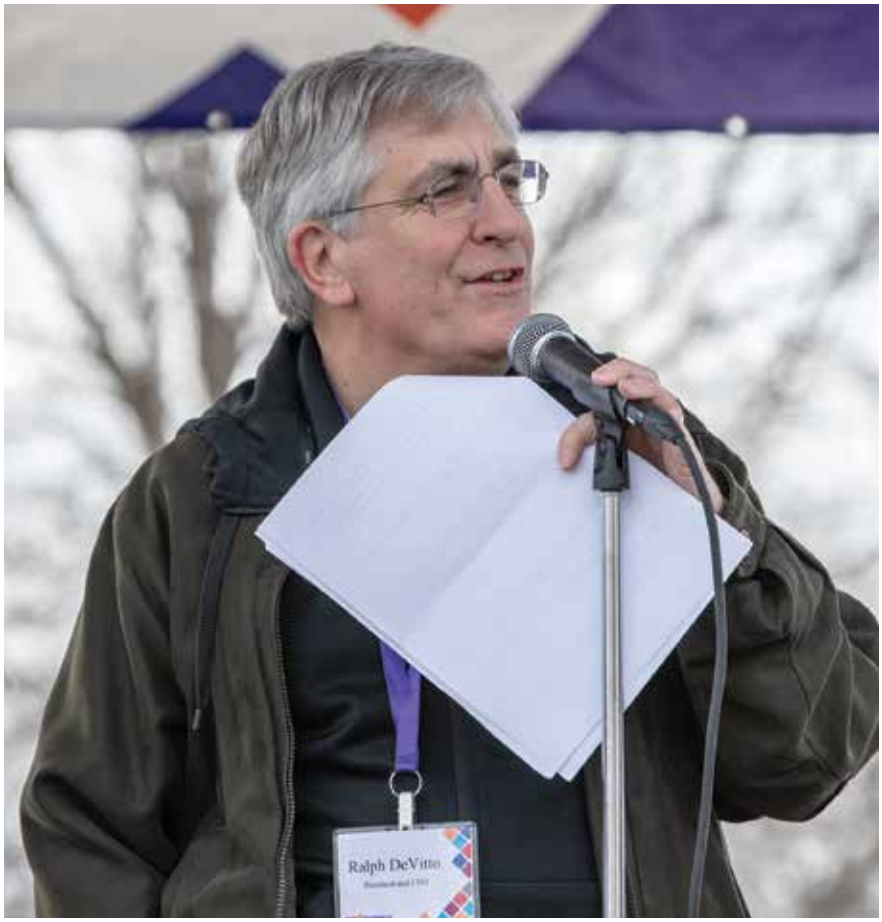
IBTA: Brain tumors are a rare cancer and bring with them some unique challenges. What has struck you so far about these challenges?
RDV: As I mentioned before, the time from diagnosis to making a treatment decision is a serious challenge that continues to be a focal point of our organization. Also, if we look at the roughly 78,000 newly diagnosed patients in the US, it is technically a rare disease but only just. But because of the rare disease distinction I think one of the biggest challenges we face is the inadequate commitment of funding for research. Also I think it is a bit of a framing issue. That number represents patients diagnosed with primary tumors only. There is a growing body of evidence that suggests that number grows to near breast cancer levels if we start to include brain metastases, where other types of cancers spread their way into the brain. We also know that once a primary cancer metastasizes to the brain, treatment challenges arise because of the blood brain barrier and other characteristics unique to the brain.

There are additional reasons why funding for research is so vital and why, in my opinion, all the brain tumor organizations in the US and around the globe should be more collaborative in our approach.

IBTA: What, to date, gives you the most satisfaction from your work?
RDV: First, I think it's the people in this organization. I am honored to serve alongside a dedicated staff at the ABTA where we have a truly selfless and passionate Board of Directors. But I think my greatest satisfaction is talking to patients and caregivers. Their resiliency keeps me going. They fight this battle day in and day out and, quite frankly, my role by comparison is not only easy, but an honor.

IBTA: What experience and learnings from your work at the American Cancer Society do you feel you will bring to the ABTA?
RDV: I loved my time with the American Cancer Society. The staff and volunteers are absolutely dedicated to winning the war against cancer. I certainly learned that the private, nonprofit sector alone cannot be successful. Government at all levels, both domestically and globally must take a leadership role, in both funding research and enacting policies that help prevent some types of cancer such as prohibiting smoking in all public places. I also learned about the power of working in collaboration with other organizations to achieve common objectives and plan to bring this approach to the work of the American Brain Tumor Association.

IBTA: What is the role you would like to see ABTA playing in the coming years?
RDV: I see the ABTA directly funding more research, serving more patients and caregivers and also working in partnership with other organizations, including the federal government and global partners such as the IBTA. I look forward to learning more about the IBTA and increasing our work together.



IBTA: How do you relax? Do you have a hobby or a sport with which you are involved?
RDV: I am not a very accomplished tennis player but I love the game. I was playing a few times a week when I lived in Florida and need to find the time to play regularly again in my new hometown of Chicago. My wife and I enjoy walking, traveling, attending tennis tournaments when we can, attending cultural functions, and spending time with family and friends.

IBTA: What would be the first three items on your wish list for cancer patients and their families?
RDV: More treatment options for the newly diagnosed, access to quality and timely care, and post treatment support including late effects from treatment. I can list a lot more if you'll allow me more than three! ■

12th Annual Kortney's Challenge continues to spread hope for pediatric brain tumor research

THE Kortney Rose Foundation is happy to announce that the 12th annual Kortney's Challenge 2 Mile Fun Run/Walk at Monmouth Park, New Jersey (US) on August 6th, 2017 was a great success raising over US $63,000 for pediatric brain tumor research. They send thanks to the more than 500 participants, corporate sponsors, volunteers and all who supported the event. Walking mileage will be added to the Walk Around the World for Brain Tumours. ■

Introducing…
The Brain Tumour Organisation of Pakistan

Komal Syed

Founder, The Brain Tumour Organisation of Pakistan

Late 2012. I remember these few months so clearly that it feels like they happened just yesterday.

My husband, Taha, loved travelling and had planned a vacation for us to Turkey on 22nd October. But a week before this he started having severe headaches and two days prior to our travel date he was admitted to hospital for further investigations. The neurologist diagnosed migraines, but Taha's sixth sense told him that this was something else and hence he insisted on getting an MRI.

On October 25th, Taha had a 3rd ventriculostomy with a biopsy that determined he had brain cancer. He then went on to have an eight-hour craniotomy to de-bulk the tumour on December 19th and the biopsy from this surgery confirmed that not only did Taha have brain cancer, but he also had the most aggressive kind there was - Taha was diagnosed with a glioblastoma (GBM).

As a young couple only three years into our marriage, it came as a sudden jolt to us that someone as young and healthy as Taha could be diagnosed with brain cancer. Words cannot do justice to Taha's larger than life personality. He was smart, he was confident, he was humble, he was extremely social, and more than anything he was a lot of fun.

Seeing someone like Taha being diagnosed with a terminal illness that takes over one's mind and body was simply devastating. It was torture for me, and I can't even begin to imagine how it made him feel. Despite this, the strength that Taha exuded was enough to keep us all positive.

Needless to say, after this diagnosis, our lives came to a standstill. The next few months were a whirlwind of events for both of us. Taha tried to cope with the changes in his mental and physical abilities and I tried to balance my full-time job alongside my caregiver role at home. In doing so, I realized that my priorities in life quickly started to shift. My husband's journey as someone battling a terminal illness coupled with my journey as his spouse and caregiver, put us center-stage into a life and world that we had never been privy to. After diagnosis, we frantically tried to educate ourselves about the disease and search for the best treatment available. Our aim was to remain positive and hopeful and we managed to have some very special moments of joy with family and friends, but I'd be lying if I said that there were no low points.

Above: Komal Syed has established the Brain Tumour Organisation of Pakistan

We experienced, first-hand, the immense care and the extreme challenges of navigating through the healthcare system both in Pakistan and abroad. Two years after Taha's diagnosis, in late 2014, as the disease started progressing, I took a sabbatical from work and focused all my time and effort on my husband's care. This was, by far, the best decision I have ever made as it allowed me to dedicate myself completely to my husband who needed me most at that time.

Our journey through Taha's illness was overwhelming and erratic as is the case for most people battling a GBM. In hindsight I realise that our journey was also extremely isolated. We were very fortunate to have an extremely strong network of family and friends (and friends like family) who were always there for us. Thanks to them we had many high points despite the grave nature of the illness. However, we knew absolutely no one who was going through something similar to this.

My husband's medical team at the Aga Khan University Hospital in Karachi, Pakistan were beyond fantastic and they went out of their way to support us as much as they could. But again, outside of medical and personal support, we had no form of non-medical support from a brain tumour community per se.

Unfortunately, three years after diagnosis, in November 2015, Taha passed away and I lost my dear husband to brain cancer.

As a young widow, re-assembling the scattered pieces of the jigsaw puzzle that my life had become, I came to terms with where life had brought me and tried to re-align my internal compass to do what matters most to me.

I relocated to Canada to be with my immediate family and started volunteering countless hours at the Brain Tumour Foundation of Canada to support those still battling the disease, with the hope of giving back in some small way. Volunteering in Canada opened my eyes to the wide array of support elements that exist for brain

Above: Taha Rafi and Komal Syed together at the French Beach in Karachi, Pakistan

tumour patients and caregivers and allowed me to see, first-hand, how they can improve the experience of those impacted by this devastating disease. I then started to wonder how it would have been for my husband and myself had these support elements been available for us during our journey.

This thought eventually brought me to the idea of establishing such a support organisation in Pakistan, which services all those impacted by a brain tumour in the country today.

The Brain Tumour Organisation of Pakistan was founded in 2018 in memory of my late husband, Mohammed Taha Rafi.

Our mission is to reach every individual in Pakistan impacted by a brain tumour with support, education, information, and research and to accurately represent Pakistan on the global brain tumour map.

Our vision is to drastically improve the quality of life for those impacted by a brain tumour in Pakistan and to help in eventually finding a cure for the disease.

Moreover, it is my personal goal to improve the journey of those still impacted by the disease in Pakistan, with the aim of making their journey easier than it was for Taha and me.

Our organisation will focus on the following three aspects:

1) Raising awareness of the disease and providing access to information for newly-diagnosed patients and their loved ones. This is a key activity that we are focusing on from the get-go. We understand how overwhelming it can be once a brain tumour diagnosis is given. It is difficult to readily find information about specific brain tumour types in Pakistan. We strive to support impacted families in this area by having accurate information available online as well as providing the country's leading cancer hospitals with information booklets which they can share with their brain tumour patients. This information we share will be catered specifically to Pakistan and to the journey of patients and caregivers who live in Pakistan.

2) Our next key focus will be on offering non-medical support to patients and their families, by either providing support services and activities by ourselves or by connecting patients to other organisations that could be helpful. A few examples of such activities include support groups in different cities, as well as virtual groups online, and psychotherapist sessions through a qualified and registered third party.

3) Finally, we will focus on raising funds for patients' treatments and also for building a national cancer registry for Pakistan, which currently does not exist. At the moment, brain tumour cases accounted for in Pakistan are very under-representative of the true situation in the country. I am confident that the better we can represent Pakistan on the global brain tumour map, the more we will be able to request support and the more accurate local research efforts will be for brain tumours in our region.

Thank you for reading my personal story and my passion. ■

The board of members for the organisation include nine other members who span various fields and are all extremely committed to the cause: Dr. Afsheen Anwer, Tanya Mirza, Nissmah Atif, Dr. Adnan Jabbar, Kashif Zia, Farhan Siddiqui, Reza Pooya, Shezad Abdullah and Faiz Chapra.

If you would like more information about the Brain Tumour Organisation of Pakistan please visit www.braintumour.pk or email us at info@braintumour.pk

Bucaramanga, Colombia celebrates International Brain Tumour Awareness Week 2017

Gabriel Vargas MD

Honorary President of the Neurological Oncology Section of the Latin American Federation of Neurosurgical Societies (FLANC) and lead coordinator of the VII International Brain Tumour Awareness Day Symposium, 2017

For the seventh year running we supported the International Brain Tumour Awareness Week 2017 with four great events:

1 Students of the Universidad de Santander (UDES), who are part of the neurosurgery research group, participated in the XIV City of Bucaramanga Marathon, on Sunday October 22nd. Throughout all of the event they were promoting the VII International Brain Tumour Awareness Day Symposium (VII Día Internacional de la Concientización en Tumores Cerebrales).

2 We organized a pre-symposium workshop on the use of intraoperative ultrasound in neurooncology addressed to neurosurgeons of Bucaramanga. The course was coordinated by the Radiologist Camilo Lara MD from Bucaramanga-Colombia and the Neurosurgeon Eduardo Lovo MD from El Salvador. It was held at Los Comuneros Hospital Universitario de Bucaramanga, on Thursday October 26th, 2017

3 A dinner talk was organized between neurosurgeons, radiotherapists and oncologists. The use of radiosurgery in neurooncology was the main topic of discussion and it helped us create strategies for multidisciplinary treatment of our patients. This was also coordinated by Dr. Eduardo Lovo on Thursday October 26th, 2017

4 On Saturday 28th October we held the VII international Brain Tumour Awareness Day Symposium at the Universidad de Santander (UDES) with the participation of more than 250 people.

Physicians, health personnel interested in the topic, students, patients and their families attended the event. We had a great scientific event with the support of international speakers, with web conferences, and many local professors from Cali, Bogotá and Bucaramanga. We had the honor to receive an amazing guest at our auditorium, Honorary President of the World Federation of Neurosurgery Armando Basso MD, from Argentina.

Neurosurgeons, neurologists, neurophysiologists, pathologists, radiotherapists, oncologists, anesthesiologists, neurosurgical assistant instrumentation students and students from the neurosurgery research group gave lectures during the day discussing diagnosis, current treatments and care of patients with brain tumours. Patients also had a brief space to give thoughts and feelings about their lives and experience during the whole process of treatment of their brain tumours.

All the activities were supported by Universidad de Santander (UDES) and its medical faculty; Clinica Chicamocha; Los Comuneros Hospital Universitario de Bucaramanga; SNOLA, (Society for NeuroOncology Latin America); Section of Neurooncology and Skull Base of the Colombian Association of Neurosurgery (ACNcx); Section of Neurosurgical Oncology of the Federacion Latinoamericana de Neurocirugia (FLANC) and different sponsors and commercial partners involved in the treatment of patients with brain tumours. The event was free for everyone. ■

Additional information at www.neurocirugiaoncologicaflanc.blogspot.com

IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE

The IBTA maintains a list of neuro-oncology and relevant cancer conferences on its website at **www.theibta.org**

Brain Tumour Foundation of India - Annual Art Festival 2017

Dr Raees Tonse and Professor Rakesh Jalali

Brain Tumour Foundation of India and Tata Memorial Hospital, Mumbai, India

The International Brain Tumour Alliance (IBTA) holds its International Brain Tumour Awareness week globally in October and various activities are planned in this regard throughout the world.

The Brain Tumour Foundation of India (BTFI) holds its Annual Art Festival every year during the same period and last year's function was held on 15 October 2017 at the Tata Memorial Centre, Mumbai. The programme started with the art competition held between various age groups where the children participated with full enthusiasm and spirit. Various prominent artists were invited to judge the competition. This was then followed by a puppet show, which the children thoroughly enjoyed.

One of the highlights of last year's BTFI Annual Art Festival was the support group panel discussion titled "*Coping with a brain tumour*". The reason for the title was apt as the diagnosis of a brain tumour is catastrophic and often leads to significant changes in physical, cognitive, behavioral and emotional effects due to the illness and its treatments. The support group panel consisted of brain tumour patients, caregivers and doctors, who helped to identify unmet needs of the patients and caregivers; create awareness about available resources; provide information about multidisciplinary care and offer practical support.

Another highlight featured the 14 children who represented India for the "World Children Winners Games 2017" held in Moscow, Russia in various sports events such as running, swimming, football, table tennis, rifle shooting and chess. The team included children who have been cured of cancers such as brain tumours, Wilms tumor, acute lymphoblastic leukemia and many other cancers. The children enthusiastically practiced for over two months under expert guidance from trained professionals to represent India in this international event. They came back triumphantly with 26 medals coming third overall. Master Kayaan, a brain tumour survivor, was named the champion of the event after winning four medals.

Above: Dr Raees Tonse

Above: Professor Rakesh Jalali

There was also a cultural progamme during the Annual Art Festival, which was performed by childhood brain tumour survivors of various age groups who actively participated in activities such

as a fancy dress competition, singing and dancing. The "*Brain Tumour Survivor Award*" was presented to three children who, in spite of their diagnosis of a brain tumour, have done exceedingly well.

The Brain Tumour Foundation of India will continue to provide medical treatment, conduct research, and provide financial assistance, psychological support and rehabilitation to these patients and their families all over the country. ■

Pictured: Children with brain tumours participating in various cultural activities during the Brain Tumour Foundation of India's Annual Art festival around the time of the October 2017 International Brain Tumour Awareness Week."

Philippines Brain Tumor Alliance: no one with a brain tumor should ever walk alone

Will and Sue Abbott, founders of the Philippines Brain Tumor Alliance (PBTA) wrote to the IBTA to say that their first formal Walk Around the World for Brain Tumours at the end of May 2017 was an extremely successful event. The Abbotts were very touched and overwhelmed by the numbers of people who participated – more than 210 supporters! Will and Sue added: "Neurosurgeon Dr Gap Legaspi, Director of the Philippine General Hospital, gave a wonderful talk. We collected a total of 510 kms from our walk which have been donated to the Walk Around the World for Brain Tumours." ■

The 6th Brain Tumor Awareness Day in Argentina

Alejandra T Rabadán, MD PhD

Chief of Division Neurosurgery, Institute of Medical Research A Lanari, University of Buenos Aires, U.B.A and Coordinator of Section of Neurooncology: Argentine Society of Cancerology

The Section of Neurooncology of the Argentine Society of Cancerology organized the "Sixth Annual Brain Tumour Awareness Day". It took place on October 24th, 2017 in the building of the Argentine Medical Association - AMA (Buenos Aires). The Argentine Association of Neurosurgery AANC; the LatinAmerican Federation of Neurosurgical Societies FLANC; and SNOLA (LatinAmerican Neuroncological Society) also gave their academic support to the meeting.

Representatives of several societies joined us:

- on behalf of the Argentine Association of Neurosugery AANC: Dr Juan J Mezzadri, VicePresident; Dr Marcelo Platas (Past President); Dr Silvia Berner (Coordinator of Tumor Section); Dr José Cascarino; Dr Roberto Zaninovich and Dr Diego Hernández

- on behalf of the Argentine Society of Radiotherapy SATRO: Dr Luisa Rafailovici (Past President); Dr Ana Martínez (Coordinator of Neuroncology Section) and Dr Máximo Barros

- on behalf of the Argentine Society of Pathology: Dr Gustavo Sevlever and Dr Silvia Christiansen

- on behalf of the Argentine Society of Cancerology: Dr Clelia Vico (Past President); Dr Marina Bramajo (Vocal); Dr Diego Prost; Dr Alejandro Muggeri and Dr Marcelo Blanco Villaba (President).

We focused on the proposal of quality management improvement, based on the findings observed in the previous Argentine survey "The accessibility to diagnostic methods and treatment of brain tumors in Argentina" published in the open access journal *Surgical Neurology International*; 2017 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5482164/).

People from different disciplines such as neurosurgery, neuro-oncology, radiation therapies, psycho-oncologists, and palliative care specialists participated enthusiastically, especially the neuropathologists, proposing possible but necessary ideas in a realistic frame.

Above: Some members of the team (from the left to right): Dr Máximo Barros (radiotherapist), Dr Ana Martínez (radiotherapist), Dr Luisa Rafailovici (radiotherapist), Dr Gustavo Sevlever (pathologist), Dr Alejandra T Rabadán (neurosurgeon), Dr Diego Prost (oncologist), Dr Alejandro Muggeri (oncologist).

We are also working with the AANS/CNS Section on Tumors to develop fellowships in the United States for young Argentinian neurosurgeons.

A great effort was made to continue with this kind of meeting, high quality from the academic point of view, and open to the scientific community with free access. Through these initiatives, we hope to continue to foster education, with the ultimate goal to provide an equitable neurosurgery practice for the people of Argentina. ■

The IBTA has released the official reports from its third biennial World Summit of Brain Tumour Patient Advocates and the Sub-Saharan Africa Neuro-Oncology Collaborative ("S-SANOC") meeting. You can read them online at **https://issuu.com/ibta-org/docs/summit_report_2017** (Summit report) and **https://issuu.com/ibta-org/docs/ibta_ssanoc-report_final_20mar2018** (S-SANOC report)

The International Brain Tumour Alliance has contacts in the following 111 countries. It also distributes its annual magazine, *Brain Tumour* in these countries:

Afghanistan ■ Albania ■ Algeria ■ Argentina ■ Australia ■ Austria ■ Bahrain ■ Bangladesh ■ Belarus ■ Belgium ■ Bolivia
Bosnia-Herzegovina ■ Brazil ■ Bulgaria ■ Cameroon ■ Canada ■ Chile ■ China ■ Colombia ■ Congo ■ Costa Rica ■ Croatia
Cuba ■ Cyprus ■ Czech Republic ■ Denmark ■ Dominican Republic ■ Egypt ■ El Salvador ■ Eritrea ■ Estonia ■ Ethiopia ■ Finland
France ■ Georgia ■ Germany ■ Ghana ■ Greece ■ Guatemala ■ Hong Kong ■ Hungary ■ Iceland ■ India ■ Indonesia ■ Iran
Iraq ■ Ireland ■ Israel ■ Italy ■ Jamaica ■ Japan ■ Jordan ■ Kenya ■ Kyrgyzstan ■ Lebanon ■ Libya ■ Lichtenstein ■ Lithuania
Luxembourg ■ Macedonia ■ Malaysia ■ Malta ■ Mauritania ■ Mauritius ■ Mexico ■ Mongolia ■ Morocco ■ Myanmar ■ Namibia
Nepal ■ New Zealand ■ Nigeria ■ Norway ■ Pakistan ■ Panama ■ Paraguay ■ Peru ■ Philippines ■ Poland ■ Portugal
Qatar ■ Romania ■ Russia ■ Saudi Arabia ■ Serbia ■ Singapore ■ Slovak Republic ■ Slovenia ■ South Africa ■ South Korea
Spain ■ Sri Lanka ■ Sudan ■ Sweden ■ Switzerland ■ Syria ■ Taiwan ■ Thailand ■ The Netherlands ■ Tunisia ■ Turkey ■ Uganda
Ukraine ■ United Arab Emirates ■ United Kingdom ■ United States ■ Uruguay ■ Venezuela ■ Vietnam ■ Yemen ■ Zimbabwe

INTERNATIONAL BRAIN TUMOUR ALLIANCE

Excerpts from the Third Biennial World Summit of Brain Tumour Patient Advocates

BUILDING BRIDGES ACROSS THE INTERNATIONAL BRAIN TUMOUR COMMUNITY

19th - 22nd October 2017

The Tower Hotel, London, United Kingdom

www.theibta.org

We would have loved to include more excerpts from the Summit report in *Brain Tumour* magazine but you can read all of the report online here: https://issuu.com/ibta-org/docs/summit_report_2017

Acknowledgements and Sponsors

The International Brain Tumour Alliance (IBTA) is grateful to the following companies for their support of the Third Biennial World Summit of Brain Tumour Patient Advocates.

We are very appreciative of the wise advice, help and support provided by the IBTA's Senior Advisors: Jean Arzbaecher, Jenny Baker, Rosemary Cashman, Maureen Daniels, Stuart Farrimond, Anita Granero, Carol Knight, Carol Kruchko, Sharon Lamb, Mary Lovely, Mary Ellen Maher, Sally Payne and Chris Tse.

We're delighted to welcome to the Summit representatives of leading brain tumour patient advocacy, support and information organisations from 29 countries around the world. Thank you all so much for your support of the IBTA 2017 Summit.

A big thank-you to our medical and research specialists, and policy and regulatory speakers who have made time in their hectic work schedules to join us in London and to generously impart their knowledge: Gelareh Zadeh, Normand Laperriere, Mark Gilbert, Alexandra Diaz Alba, Hariz Hassan, Teddy Totimeh, Terri Armstrong, Elias Pean, Jeff Sloan, Madeline Pe, Rakesh Jalali, Suzanne Wait, Shannon Boldon, Brian Nyatanga and Stuart Farrimond..

Grateful thanks go to Ms Christine Quah, Manager, Global Accounts, HelmsBriscoe (www.helmsbriscoe.com) for her invaluable help in finding and securing our Summit venue.

Many thanks also to The Tower Hotel, for their help with our accommodation and conference arrangements.

The Third Biennial World Summit of Brain Tumour Patient Advocates, a project of the International Brain Tumour Alliance (IBTA), is a wholly independent activity and has been conceived, planned and carried out by the IBTA. For details of the IBTA's sponsorship and transparency policies, please see www.theibta.org

Day One

Welcome address

Eighty-five participants from the four corners of the globe attended the IBTA 2017 Third Biennial World Summit of Brain Tumour Patient Advocates held at The Tower Hotel, London, UK from 19 to 22 October.

Above: Eighty-five people participated in the IBTA World Summit at The Tower Hotel, London, from 19 to 22 October 2017 (not all participants are pictured)

Above: IBTA Senior Advisors Jean Arzbaecher (left) and Mary Ellen Maher (right) organised the World Summit registration desk

Above: The IBTA family globe – decorated with coloured stickers showing some of the countries represented at the World Summit

Photos by MVF Studios

Delegates included representatives of patient advocacy groups, patients, current and former caregivers, medical professionals, representatives from the Summit's sponsoring companies and others.

"We are all brain tumour experts in our own ways," said Kathy Oliver, IBTA Chair and founding Co-Director, who welcomed everyone to the Summit.

To demonstrate visually where participants had travelled from, a huge inflatable globe was placed on the stage, decorated with coloured stickers indicating all of the countries represented.

"This year's Summit is particularly special," Kathy said, "because it follows immediately after a unique one-day event: the sub-Saharan Africa Neuro-Oncology Collaborative (S-SANOC) planning meeting which the IBTA organised with the Society for Neuro-Oncology (SNO) and the Zimbabwe Brain Tumour Association (ZBTA). This meeting, which was also held here at The Tower Hotel, is a first in the brain tumour world. It involved physicians, surgeons, researchers, brain tumour patients, current and former caregivers and patient representatives from across the African continent and beyond who came together yesterday to create plans for establishing a strong brain tumour collaboration across this diverse region."

Turning to the World Summit programme, Kathy encouraged all delegates to take advantage of the presence of some of the world's leading brain tumour specialists and ask them questions in the sessions. She also urged everyone to take the opportunity to share their stories with other advocates and to create new collaborations.

Above: one of the Summit welcome slides

Above: IBTA Chair and Co-Director Kathy Oliver

Photos by MVF Studios

Let's talk about... brain tumours in the Czech Republic

DR HARIZ HASSAN is a radiation oncology resident in Prague. He is originally from Malaysia. As well as professional experience working in the field of brain tumours, he also has personal experience, having lost a sister to a brain tumour.

Above: Dr Hariz Hassan: "Being at the Summit has given me a very new experience - being surrounded by patient advocates is quite different to my professional life…"

"My sister died of a brain tumour at an early age," said Dr Hassan. "And I remember that when I was a child, I wrote down that when I grew up I wanted to be a neurosurgeon. This was at a time when my friends were dreaming of being firemen and astronauts."

Dr Hassan has lived in the Czech Republic for eleven years.

"Being at the Summit has given me a very new experience – being surrounded by patient advocates is quite different to my professional life as I normally see people from the other side."

Since 2006 the Czech Republic has been considered a developed country and there is a high quality of life. Residents prefer the Czech Republic to be called a 'Central European nation', rather than being considered in 'Eastern Europe'. The country has a high-quality universal healthcare system, ranking two places above the UK in the 2016 Euro Health Consumer Index. Healthcare is paid for by mandatory employment-related insurance plans and the government covers costs for people who are unemployed. Everyone in the Czech Republic has a GP (family doctor) and although private hospitals exist, care is primarily socialistic. The country also has high-quality cancer and death registry data. Rates of brain tumours are equivalent to those in the USA, although mortality in the Czech Republic is higher.

For a country of just 10.6 million people, there are 15 comprehensive cancer centres offering brain tumour treatment. The first neurosurgery clinic opened in 1953, and although adults are well catered for – there are four neurosurgery services in Prague alone, for example – care for paediatric patients is still lacking. The two centres specialising in paediatric brain tumour treatment are far apart, making care difficult for families who do not live near either centre.

There are a good number of auxiliary services for cancer care, which include a CyberKnife facility in Ostrava, and a Gamma Knife unit in Prague, in addition to a proton therapy centre (which was the subject of a high-profile case in the UK of a child, Ashya King, who travelled to Prague for brain tumour treatment).

Dr Hassan explained that the largest NGO (non-governmental organisation) for cancer patients is the League Against Cancer Prague (LPR), which has 58 member organisations. However, in the Czech Republic there are no NGOs dedicated solely to brain tumours and no support groups specifically for brain tumour patients, caregivers and families.

"I entered oncology because I wanted to offer more continuity of care to patients, but this has not always been possible," said Dr Hassan. "I was extremely moved when I met a woman who was caring for her husband, who had a brain tumour, while also raising her children. I felt she was missing support, and there wasn't even a facility for her to call for a specialist nurse or for extra support. So I'm in the early phases of establishing a support group for brain tumour patients in the Czech Republic. Other cancers have support groups but brain tumours do not. We have high quality personnel, but there is still a great unmet need for brain tumour patients in our country."

Photos by MVF Studios

Understanding the role of the regulator

DR ELIAS PEAN is Product Lead at the European Medicines Agency (EMA) in the Office of Oncology, Haematology and Diagnostics. He is a Doctor of Pharmacy and has worked for eight years with the EMA. Among his responsibilities, he has been involved in the evaluation of oncology products.

Key points:

- The European Medicines Agency (EMA) is the centralised body that governs the regulation of medical treatments across the European Union (EU), which covers 500 million people, in 28 Member States, who speak at least 24 different languages.
- The EMA facilitates development and access to medicines, evaluates medicine applications for marketing authorisation, monitors the safety of medicines, and provides information to patients and healthcare professionals on human (and veterinary) medicines.
- The EMA is not involved in the pricing of medicines, which is decided within individual countries.
- The EU represents 27% of the global medicine market.
- Brain tumour medicines are regulated by the Committee for Human Medicinal Products (CHMP), which is one of the EMA's seven committees, and it appoints working parties to oversee specific areas.
- Patients have a voice in many stages of the EMA approval process, although it has taken many years for them to be fully integrated and work is ongoing to involve them more.
- The EMA prides itself on transparency and independence, and all agendas and documentation of the decision-making process are published online so that anyone can scrutinise them.

The EMA is a body of the European Union (EU) – a political and economic union made up of 500 million people, in 28 Member States, who speak at least 24 different languages. Twenty-seven per cent of all global medicine sales take place in the EU, and the EMA's mandate is to protect both human and animal health. This involves:

- facilitating development and access to medicines
- evaluating medicine applications for marketing authorisation
- monitoring the safety of medicines
- providing information to patients and healthcare professionals on human (and veterinary) medicines.

The EMA is not involved with pricing and reimbursement of therapies – this is decided in individual countries (and is sometimes even done on a regional level).

"The EMA is a large organisation made up of 890 staff collaborating with a network of 4,000 scientific experts from across the continent. We have seven scientific committees and 28 working parties. We coordinate with 50 public health authorities. Decisions need to be made by bringing together all 28 countries," Dr Pean said.

There are two ways that medicines can be approved: **(1)** on a country-specific level or **(2)** for the whole EU. Most innovative medicines take the latter route. Regardless of the authorisation route, all products follow one set of common rules. The centralised process means that one medicine or treatment has one application, one evaluation, and one EMA authorisation which applies to all EU Member States. Following EMA approval, pharmaceutical companies are obliged to

Above: Dr Elias Pean, Product Lead at the European Medicines Agency (EMA)

Photos by MVF Studios

Above: The EMA's Dr Elias Pean explains the roles that patients and patient advocates can play at the European Medicines Agency

market the drug in at least one of the EU countries.

Seven EMA committees are involved in drug development and evaluation, each of which deals with a different sphere. These committees include:

- Paediatric Committee (PDCO)
- Committee for Orphan Medicinal Products (COMP)
- Committee for Advanced Therapeutics (CAT)
- Committee for Human Medicinal Products (CHMP), which is responsible for the scientific evaluation/authorisation of all medicines including brain tumour medicines.

All EMA committees are made up of scientific experts and representatives from each Member State. Each of these committees has working parties focussing on different areas. The committees can choose to convene extra scientific advisory groups, such as an oncology or neurology advisory group, when more expertise is needed.

It is not only pharmaceutical companies, but academics also, who can interact with the EMA on drug development. For rare diseases, such as brain tumours, it is possible for therapies to be given approval when there is less comprehensive data providing there is "sufficient positive benefit balanced against the risks."

Processes in the USA and other parts of the world have different mechanisms for approving medicinal treatments.

Independence and transparency are key principles at the heart of the EMA approval process. All scientific experts are assessed to ensure they have no financial conflicts of interest. Two countries will always perform their own independent assessment of any medicine for which approval is sought. All minutes, agendas and documentation of the decision-making process are published so they can be scrutinised by the public.

"Patients have a voice in many stages of the EMA approval process, but it has not always been that way," said Dr Pean.

"The EMA was established in 1995, and dialogue with HIV patients first took place in 1996. Since then, the COMP welcomed patients as full members in 2000, and a Patients and Consumers Working Party (PCWP) was created in 2006. A dedicated Patients and Healthcare Professionals Department was created in 2014."

By 2016, patients/consumers were involved with the EMA on 750 occasions – a tenfold increase over ten years. 'Real life experience' has been systematically included in the EMA's regulatory output since 2017, and there are plans to further expand patients' roles in the future. Most recently, the EMA conducted its first public hearing, where patients, caregivers, healthcare professionals and academia shared their experience with valproate, a medicine used in epilepsy, bipolar disorder and migraine.

Today at the EMA, patients are involved in every step of the lifecycle of a medicinal product, including 'orphan designation' decisions, scientific approvals, marketing authorisations and drug evaluation. Patients are also involved in the review of information leaflets and safety information, which is distributed with medicines.

"Patients can be recruited as representatives of the patient community, specific organisations, or acting as independent experts. The ways that patients engage with the process are varied and include face-to-face meetings, written submissions, committee meetings, conference calls and surveys."

Photos by MVF Studios

Let's talk about… challenges in serving a geographically-dispersed brain tumour community in Australia

CATHERINE HINDSON is Chair of Brain Tumour Alliance Australia (BTAA).

In 2010, Catherine's daughter was diagnosed with an anaplastic astrocytoma. After a period of misdiagnosis, she was eventually sent from the family home in Canberra to Sydney (a distance of 150 miles/250 km) for surgery.

"While my daughter was still in hospital," Catherine said, "she found Brain Tumour Alliance Australia via internet searches. My search for support also led me to Denis Strangman (co-founder and former Chair of the IBTA). We found help by being proactive, but most people aren't so lucky. My goal is that every patient is given a brochure of where to find support in Australia.

"Many tourists regard Australia as a dangerous place because of its sharks, crocodiles, and venomous snakes. However, such fears are disproportionate because there are only a handful of deaths due to snakebites, shark, and crocodile attacks each year. By comparison 1,200 Australians die from brain tumours annually from a total of 1,600 malignant and 3,000 benign tumour diagnoses."

Catherine offered some perspectives on the vast size of Australia, which presents many issues for effective and efficient brain tumour care. At almost 7.7 million square kilometres in size, Australia is larger than the UK and Europe combined, and is roughly equivalent in size to North America.

Displaying a map of the country with the population density highlighted, it was clearly apparent that there were concentrated areas in some coastal regions but with many "empty" areas as well. The Australian population is very scattered with nearly 20% of the country's centre being desert.

Though a vast landmass, the population is only around 24 million. It is estimated that there are 34 million kangaroos!

By way of comparison, Sydney has five million people – a similar population to Barcelona – but

Above: Catherine Hindson, Chair of Brain Tumour Alliance Australia (BTAA)

Photos by MVF Studios

is four times larger. Melbourne is the same physical size as London, but has half the population.

The wide population distribution provides significant challenges for provision of services. Australia's health care system is a web of public and private providers, with each of the country's six states managing its own health care funding, thus making it potentially problematic for patients travelling between states for treatment.

A government-funded Medicare system offers universal healthcare, but gives patients no say in the choice of doctors who treat them. The private health care sector is only partially covered by private health insurance, although private care does give brain tumour patients the choice of surgeon. Seeking the best treatment is expensive. In Australia, if you have no private medical insurance, electing to have private surgery with a top neurosurgeon can cost AUD$85,000 (equivalent to US$65,000), which is slightly more than the average annual salary.

Compounding the challenges further, is the problem that brain tumour surgery is only offered in specific locations. An image of the Australian map, with locations of brain surgery units highlighted, showed that the service is scattered, being available in Sydney, Melbourne, Brisbane, Townsville, Perth, Canberra, and Tasmania.

Catherine told the Summit: "Keep in mind that Australia is a very large place. Imagine living in Broome, a town on the North West coast, and having a brain tumour. It's a 2,200 kilometre drive to treatment in Perth, or a four-hour flight, costing around $1,000 - if you get a cheap one."

Even Darwin, the capital city of the Northern Territory, with a population of 140,000, is a 33-hour drive from the nearest hospital that performs brain tumour surgery.

Much like her own experience, Catherine said that many brain tumour patients are sent home without any knowledge of support groups, or where to get help. There are presently 16 brain tumour support groups in Australia, but most provide a service only for those living in the near area (and one support group is only for glioblastoma patients).

Support services are also not distributed according to where the need is. Australia's second largest city, Melbourne, is well served, while the largest city, Sydney is less so.

Catherine said that Brain Tumour Alliance Australia (BTAA) provides the only national support group. "We have a website where people can request information and we have a 24-hour freecall phone line. We also have face-to-face support groups in Canberra and Sydney, with plans to expand to regional Victoria and Tasmania early in 2018. We are looking to expand their service further, and presently stream meetings from Sydney to another support group in a regional town 200km away."

Catherine summarised the five key challenges BTAA faces in serving a geographically-dispersed brain tumour community:

1. letting patients know what support is available
2. meeting the cost of providing support (no central government funding is received)
3. overcoming distance barriers
4. overcoming technology limitations (internet coverage is poor in some regions)
5. meeting the needs of a multi-cultural society. On this last point, Catherine said that half of all people in Australia were born overseas (a quarter of whom have arrived since 2012), and over 300 languages are spoken.

In response to these challenges, BTAA:

- sends out information packs by post
- provides multi-language resources
- funds national and regional patient forums
- connects brain tumour fundraising and regional support organisations
- supports group leader development
- provides regular, national printed and email newsletters and online support pages.

BTAA's priorities for the future, developed in 2016, are as follows:

- to support
- to inform
- to represent
- to connect

They have appointed a director for each priority. Catherine gave some examples of how they are addressing these priorities. They are investigating translation services for informing people, BTAA is connecting with others via scientific conferences (such as the annual meeting for COGNO - Cooperative Trials Group for Neuro-Oncology); and they are representing the brain tumour community through submitting requests to the government to discuss cancers with a low survival rate.

One man's surprising journey: from brain tumour to biscuit dunking

Above: Dr Stuart Farrimond gave an entertaining and inspiring presentation on how being diagnosed with a brain tumour changed his life in ways both bad and good

DR STUART FARRIMOND is the IBTA's Digital Technology Advisor (UK). He gave an overview of how his life had changed - in ways both good and bad - since he was diagnosed with a brain tumour.

Stuart Farrimond described his life as a hospital doctor, just over ten years ago, in the historic city of Bath in the UK. He had recently married and was working long hours, with a lengthy commute to and from work by bicycle.

Dr Farrimond explained that excessive exercise and insufficient rest had led to low energy levels and fatigue. Seeking medical attention from his GP, blood tests revealed that he had extremely low levels of testosterone and thyroid hormone. Because several hormones were out of balance, he was referred for an MRI brain scan to check that the pituitary – a small gland at the base of the brain – was not damaged.

He received his MRI scan during a working day at the hospital and was one of the first people to see the images. The next day, he was rushed in to see a neurologist who confirmed a diagnosis of glioma. Showing slides of his scans to the Summit participants, Dr Farrimond highlighted a large mass in the right, frontal region of his brain.

These were dark times, but he chose to make good out of a bad situation and organised a sponsored 100-mile cycle ride with his brother-in-law for the charity Brain Tumour UK (now incorporated into The Brain Tumour Charity).

Dr Farrimond's story was picked up in the local press, radio and the medical press, leading to an outpouring of donations that touched him and restored his faith in humanity. The route was from the city of Bath to the Isle of Wight, off the south coast of England, and about £10,000 was raised for the charity. The ride led him to meet Jenny Baker, then

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Chief Executive of Brain Tumour UK, and Professor Geoff Pilkington, a prominent brain tumour researcher who coincidentally lived on the Isle of Wight. These relationships would later pave the way to Dr Farrimond's involvement in brain tumour advocacy.

He had his first brain tumour operation one month after diagnosis to resect the tumour. The pathology analysis revealed it to be a grade II astrocytoma. He described the harrowing experience of being discharged from hospital 48 hours after surgery, only to suffer an epileptic seizure the following night. This caused profound, ongoing worry for both he and his wife and, despite antiepileptic medication, he continued to have occasional gran mal seizures.

Dr Farrimond explained that he tried to return to work but highly-debilitating fatigue, and ongoing seizures meant that he was ultimately forced to leave medical practice on health grounds. To add insult to injury, his wife was diagnosed with multiple sclerosis within a year of his brain tumour being discovered. Dr Farrimond described a second neurosurgery to resect potential regrowth eighteen months after his first operation. Since this time, he has experienced no further full-body epileptic seizures.

"I never much liked working in hospital medicine," he said.

Dr Farrimond described life as a junior doctor being like "a little cog in a big machine – you often don't know whether you are actually helping patients."

Before his diagnosis, he began his training for General Practice to become a primary care physician. But being forced to leave medicine meant that he could spend more time with his wife and, ultimately, enjoy his life more.

Above: Dr Farrimond draws names out of a hat for the winners of his new book on the science of cooking

Above: Stuart Farrimond has written a food science book and he has recently made national radio and TV appearances to promote the book which is called 'The Science of Cooking: Every Question Answered to Give you the Edge'

Dr Farrimond then worked as a lecturer in a local college, teaching 16-19 year-olds the scientific components of a health and social care qualification. It was during this time that he discovered a joy for teaching and seeing young adults, who came in thinking that they hated science, leave the course with an excitement for the subject.

"It was more satisfying than anything I had ever experienced in medicine."

It was during this time that he started writing a science-themed online blog.

Dr Farrimond worked in teaching for three years but increasing work pressure took a toll. When he was awarded a financial grant from the Wellcome Trust for a science-themed digital magazine he had established, he stepped down from teaching to pursue a full-time career as a freelance science writer.

Serendipity led Dr Farrimond into mainstream media. A tongue-in-cheek blog article he wrote while working as a teacher called 'The Science of Biscuit Dunking' was picked up by a BBC television producer soon after Dr Farrimond left teaching. He was asked to 'do the science bit' in a food documentary which featured the well-known UK television cook Nigel Slater.

Since that first experience on national British television, Dr Farrimond has been regularly contacted by media outlets. "I somehow fell into a food science

Photos by MVF Studios

niche and broadcasting work gradually built up."

His achievements include writing for national magazines and newspapers, hosting a weekly local radio science slot, conducting food science research and media appearances for private companies. Now a regular guest for the BBC News television channel, he reviews the weekend newspapers.

"I would never wish to have a brain tumour, but it has given me opportunities to do things I would never have dreamed of," said Dr Farrimond.

The book publisher DK (Dorling Kindersley) contacted Dr Farrimond last year asking him to write a food science book. It was published just prior to the 2017 IBTA World Summit of Brain Tumour Patient Advocates and he has recently conducted national radio and television appearances to promote his book. He was delighted that the book was selling well and that it was being enjoyed by so many people. He said: I discovered life after being a doctor."

To conclude his talk, Dr Farrimond showed a video montage of his various television appearances, which caused laughter and smiles among the audience.

Earlier in the Summit, he had invited delegates to write their choice of a 'perfect meal' on a piece of paper and place their choice in his hat. At the end of the talk he randomly picked out two entries, one of which was that of Tina Mitchell Skinner (founder of Brain Tumour Support, UK) and the other was that of Maria Solomou (Cyprus Brain Tumour Association) who were then each given a signed copy of Dr Farrimond's book to take home as a memento.

Above: …and the winners are: Maria Solomou (back, Cyprus Brain Tumour Association) and Tina Mitchell Skinner (front, left, Brain Tumour Support, UK)

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Masterclass

Rare CNS tumor program: implementation of the Cancer Moonshot Rare Tumor Patient Engagement Network

DRS MARK GILBERT and TERRI ARMSTRONG facilitated a masterclass on the Rare Tumor Patient Engagement Network which they introduced on Day One of the Summit (see "State of the art: systemic treatments").

Key points:

- Rare tumours, which include brain and central nervous system tumours, collectively make up 27% of cancers diagnosed and lead to 25% of cancer-related deaths.
- The relative rarity of brain tumours – especially the less common brain tumours – presents particular challenges for effective patient care and research.
- The Rare Tumor Patient Engagement Network seeks to improve patient care, make it easier for patients to access clinical trials, and to facilitate research into new therapies, through the development of an easily-accessible, collaborative international network.
- The National Institutes of Health (NIH) in the USA has resources uniquely suited to deal with brain tumour research.
- Adopting more flexible, adaptive clinical trial designs will help overcome the hurdles presented by relatively low patient numbers, while hopefully offering better outcomes for trial subjects.
- Recruiting sufficient numbers of patients with rare tumours in order to achieve meaningful research is an ongoing challenge that requires a high level of patient advocacy group involvement.

Rare tumours contribute significantly to the overall burden of cancer. Collectively they make up 27% of cancers diagnosed each year and lead to 25% of cancer-related deaths. All paediatric cancers and primary brain and central nervous system tumours are rare and present significant unmet need for therapy.

There are substantial challenges associated with rare cancers. These include the facts that:

- Rare tumours often take a long time to diagnose and when identified are often at advanced stages.
- There is limited social and advocacy support for people with rare tumours.
- Most medical centres have limited experience of rare tumours, forcing patients to search hard for experts who are sometimes located in countries other than the one where the patient lives.
- There is often no established standard of care for rare tumours, which further amplifies the uncertainty faced by patients
- There is a lack of clinical trials for patients with rare tumours.

One of the aims of the Rare Tumor Patient Engagement Network is to directly address these challenges (and others) and make it easier for patients to access research and treatment. This will be achieved by developing an easily accessible, national and international patient engagement network for rare tumour research and patient care.

It is not only patients with rare tumours and their families who face challenges. Researchers do as well:

- It takes a long time to accrue enough patients with rare tumours for clinical trials to yield robust results with evidence of strong treatment effects.
- There is a lack of animal and cell-based 'models' for lab-based research into rare tumours.
- Fund-raising to support the high cost of research into rare tumours is a challenge because rare tumours do not attract the public attention that high profile cancers (such as breast cancer and leukaemia) do.

The Rare Tumor Patient Engagement Network will deal with some of these obstacles by forming a collaborative, well-funded research network for rare

Above: Dr Mark Gilbert (right) and Dr Terri Armstrong (left), both from the Neuro-Oncology Branch at the National Institutes of Health, USA

tumours that will promote development of new therapies and better standards of patient care.

Dr Mark Gilbert and Dr Terri Armstrong are based at the National Institutes of Health (NIH) in Bethesda, Maryland, USA. The NIH's resources are uniquely suited to deal with brain tumours and other rare tumour research.

The NIH will offer clinical trial and treatment resources such as travel costs, investigative support, clinical and laboratory data management support and the use of NIH social media networks.

The project will employ the CERN Foundation model. CERN (Collaborative Ependymoma Research Network) is a highly successful endeavour focussing on the clinical outcomes that matter most to patients. Dr Gilbert highlighted some of the projects at CERN to demonstrate how it focuses on integrating basic research into clinical testing. CERN has also worked closely with patients and patient advocacy groups.

CERN's first research project had dramatic results. It tested a drug called lapatinib alongside temozolomide chemotherapy. This used an adaptive approach that gave all patients the active treatment. Progression-free survival in the study was 44%. But perhaps most importantly, patients had major symptom improvement even when changes on MRI scans were small.

"We learned not to just look at imaging results," said Dr Gilbert.

A second project, led by Dr Armstrong, collected ependymoma tumour samples and clinical data from nearly 700 patients. These samples contributed to analyses that led to the present understanding that ependymoma exists as seven distinct subtypes.

A third CERN project used large libraries of drugs and bioactive chemicals already in existence such as the collection held by the US Food and Drug Administration. These were systematically screened for any potential effect they may have on ependymoma. Researchers developed mouse models and molecular methods for high-speed screening and these new techniques will be an important tool for future research.

Dr Terri Armstrong then explained another CERN project: 'The Ependymoma Outcomes Project'. This focused on discovering what the ependymoma patient experience was.

"Recruiting patients for this research was a major challenge," she said, "There were less than 100 patients with whom we had direct contact. We launched a successful online survey and luckily reached enough people. What we found was very troubling. Our research showed that ependymoma has a significantly high impact on quality of life. Patients were very symptomatic, despite being told they had a low-grade tumour. They were suffering substantial pain and patients with spinal tumours were often taking narcotics for relief. Patients also said that they had fragmented care and the majority were not cared for at specialist centres. These findings led to two published papers, one of which solely explored the social impact of ependymomas."

Dr Armstrong said that given the great unmet need revealed in this research, the next stage was to reach out to more patients. This was done using a variety of online strategies including social media (Facebook, Twitter and YouTube), a web-based portal which included educational material, publishing patient stories, distributing a quarterly newsletter, and launching Ependymoma Awareness Day and Ependymoma Awareness Month activities.

"Social media was effective at communicating with patients and running surveys. Facebook required extra effort, however, because comments needed to be moderated."

Among the ependymoma awareness-raising activities is the annual butterfly release, which runs in partnership with the US National Brain Tumor Society's annual Head to the Hill event in Washington DC. The butterfly release is broadcast live online and the initiative has rolled out worldwide, with many groups now releasing hundreds of butterflies to honour loved

Photos by MVF Studios

ones with ependymoma, caregivers, and to support ependymoma research. The ependymoma community has also created a series of videos as a resource for patients together with a guide about diagnosis, treatment and other aspects of life with ependymoma. Results of CERN's surveys are published online and freely available to all.

"We couldn't have learned what we did if we only went to major institutions," Dr Armstrong said. "We are continuing to expand our repository of tumour tissue and now trying to reach low-income patients, who are under-represented and at highest risk of not receiving adequate care. We've been able to expand our epidemiology [health statistics] work and a project started in August 2017 is looking at risk factors associated with ependymoma. Thanks to the facilities available to us at the NIH, we have arranged for patients to complete online surveys, after which they will be sent a sampling tube for saliva [for DNA analysis for research purposes] which can then be sent back to us through the mail free-of-charge."

The Rare Tumor Patient Engagement Network will be web-based, with all results published online thus publicly available so as to be of use to future research. Across the USA, 32 medical and cancer centres have signed up to collaborate and the Network is expanding internationally. Partnering in this project with patient advocacy organisations is a priority and there will be yearly meetings for sharing feedback and giving input.

Above: Kathy Oliver (Chair, IBTA): "The Rare Tumor Patient Engagement Network is a fantastic opportunity for the international brain tumour community."

Plenary Session

Clinical Updates from Health Care Professionals

State of the art: brain tumour surgical treatments

DR GELAREH ZADEH is a neurosurgeon-scientist. She is Head of Surgical Oncology at University Health Network and Head of the Toronto Central Regional Cancer Program at Cancer Care Ontario; and also the Program Medical Director for the Krembil Neuroscience Centre at Toronto Western Hospital, Canada.

Key points:

- Technology has become increasingly incorporated into neurosurgery over the past twenty years.
- Functional MRI scanning now visualises brain pathways to reveal how they correlate with a brain tumour.
- Gliomas and other infiltrative tumours seed the brain with microscopic deposits, presenting one of the greatest surgical challenges for brain tumour removal.
- Therapies targeting brain tumour cells which are distant to the main tumour mass should be prioritised.
- Viral-based brain tumour therapies are the subject of exciting research.
- Mass spectroscopy, a technology that allows rapid molecular diagnosis of a tumour during surgery, can potentially help guide the neurosurgeon.

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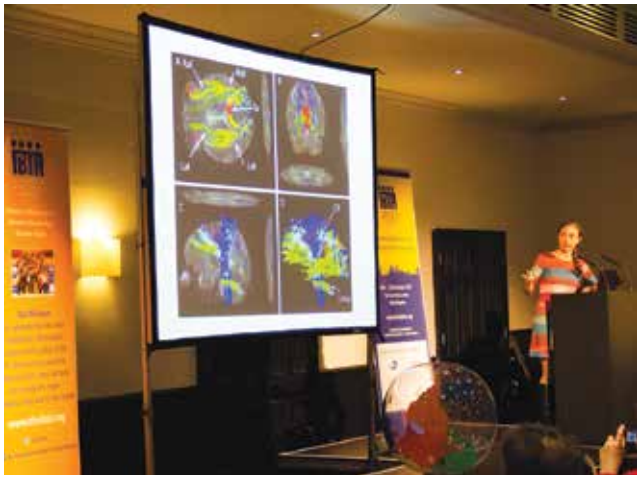

Above: Neurosurgeon Dr Gelareh Zadeh (Canada)

Giving an up-to-date overview of surgical treatment for gliomas, Dr Zadeh discussed the history and evolution of brain tumour surgical therapies, current techniques, and future treatments under investigation.

"The past 20 years have seen widespread incorporation of technology into surgical procedures," Dr Zadeh said, "but surgical treatments have limitations and brain tumours pose particular challenges which include variability in technical expertise between surgeons across institutions and, critically, the variability within the tumours themselves. There is a need to move toward targeted therapy."

Dr Zadeh discussed early stereotactic techniques and how they have developed. Conventional head frames, such as the Leksell and CRW (Cosman-Roberts-Wells) apparatus, fix onto a patient's skull and guide the surgeon during tumour biopsies for diagnosis and histopathology (examination of cells in a laboratory). Pioneered more than fifty years ago, these techniques have evolved into modern devices using lasers for guidance. But even the newest apparatus is imperfect. Stereotactic biopsy has a sampling error of 33-66% for low-grade astrocytoma and 40% for anaplastic astrocytoma.

Biopsy is generally only used in cases involving:

- deep-seated tumours
- brainstem and pineal region tumours
- patients aged 70+ (with intent to give palliative care)
- brain tumours involving eloquent cortical structures (areas that directly control function, such as movement) – which may also warrant awake surgery.

For tumour removal (as opposed to a biopsy) functional MRI (a form of MRI scanning that detects areas of brain activity) may be used for tumours near eloquent brain structures.

"Functional MRI offers many potential benefits, revealing pathways within the brain that correlate with the location of the tumour." Dr Zadeh said. "It can also be used with contrast imaging to potentially indicate whether a tumour is high or low grade. Nevertheless, surgeons tend to rely on awake surgery procedures rather than solely on functional MRI. Directly stimulating areas of the brain while the patient is awake can accurately identify tumour boundaries."

There are other technologies like mass spectroscopy, a technique for identifying specific molecular types within a tissue sample and angiography, which shows vascularity (blood supply) and helps maximise safe resection (removal of the tumour).

Dr Zadeh explained that: "It can be difficult to tell the difference between a brain tumour and healthy brain tissue. There is no pain felt from the brain's surface. So electrode stimulation while the patient is awake identifies eloquent brain structures before any tissue is removed. EEG (electroencephalography) is used at the same time to detect whether an epileptic seizure has been triggered. Our ability to integrate technology into surgical treatments has, I believe, plateaued. Brain tumours are diffuse diseases – gliomas migrate through white matter tracts and invade tissue distant from the tumour mass. This poses perhaps the greatest challenge to surgeons."

Asking "How do we target these cells?" Dr Zadeh described novel therapies in current clinical trials. One such approach targeting migrated cells that is becoming more popular is called viral-based intratumoral delivery of therapeutics. During neurosurgery, viral-based therapeutics are injected into the brain which target and destroy tumour cells distant to the main tumour mass.

"One such approach is Toca 511 and Toca FC. This technology uses a modified retrovirus (Toca 511) that infects and replicates inside tumour cells. The virus, which has limited effect on healthy cells, is delivered directly into the brain during surgery but then spreads and infects remaining tumour cells throughout the brain. The viral vector carries a 'prodrug' which converts into the chemotherapy drug 5-FU when Toca FC is administered via an oral tablet, turning

Photos by MVF Studios

Above: Dr Gelareh Zadeh reviewed the latest approaches in surgical treatments for gliomas

the tumour cells into 'chemotherapy factories' while simultaneously activating the immune system."

Another approach is the DNX-2401 oncolytic virus trials with which Dr Zadeh's team is involved.

She said: "The agent is a genetically-engineered adenovirus that safely infects and replicates inside brain tumour cells, ultimately leading to their destruction. Like Toca 511 and Toca FC, this therapy also stimulates the immune system to attack tumour cells. The virus replicates in human tumours for a period of weeks to months, causes tumour tissue death during this time and stimulates immune cells to infiltrate the tumour. Our experience with phase 1 trials of DNX-2401 demonstrates few toxicities. On MRI scans, there is also evidence that it leads to long-term tumour tissue destruction."

The protocol for an ongoing phase 2 trial of DNX-2401 in combination with the drug pembrolizumab for patients with recurrent glioblastoma or gliosarcoma, will reveal more about the safety and efficacy of this therapy.

Surgeons are often anxious about how much tissue to remove. The intraoperative molecular diagnosis of brain tumours has the potential to help with this quandary. The 'molecular signature' of a tumour can influence the course of the disease, and knowing this information at the time of an operation can help guide the surgeon on how aggressive their resection should be.

New technologies can rapidly determine the molecular subtype of a brain tumour. Data show that gliomas with a mutated IDH gene produce higher levels of 2-HG – a substance which can be measured directly with specialist equipment called HPLV (High Pressure Liquid Chromatography) mass spectroscopy. This process takes about an hour - approximately the same amount of time for a surgeon to perform a resection. Technological advances mean that surgeons will have important molecular information before an operation finishes. IDH mutations are associated with a better outcome. Knowing this information might make it possible for a surgeon to administer IDH mutation-targeted therapies directly into the brain.

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Masterclass

What's new in clinical trial design?

This first masterclass was chaired by JENNY BAKER (IBTA Senior Advisor, UK), and led by DR NORMAND LAPERRIERE, Head of Ocular Oncology at Princess Margaret Cancer Centre, Canada, and Professor in the Department of Radiation Oncology at the University of Toronto.

Key points:

- Clinical trials are conventionally termed 'phase I, II and III', each phase serving a different research purpose and needing to be completed in consecutive order before a drug can be sent for approval and then released onto the market.
- Phase 0 trials are occasionally used to test a new drug in a small number of people to see how the drug is handled in the body.
- Phase IV trials are conducted after a therapy is on the market to look for rare side effects/toxicities missed in phase III testing.
- Conventional trials follow strict protocols and have a set minimum number of patients and pre-determined outcome measures. Trials are costly and time-consuming to set up and there is typically a delay of two to three years between phases.
- 'Adaptive' trials are a modern innovation that make use of advances in molecular testing and allow for conditions to be altered after a trial has started. Treatments can be tailored to the genetic make-up of an individual's tumour, and dosages altered according to the results as they are collected. New drugs can be added, and ineffective therapies can be removed from the trial as it progresses.
- Adaptive trials are generally considered more efficient and cost-effective – a phase II trial can progress into a phase III trial, for example, without stopping.
- INSIGhT and GBM AGILE are examples of adaptive trials in brain tumours.

Above: Set against the backdrop of the River Thames in London, the IBTA Summit masterclasses were a popular part of the 2017 IBTA World Summit of Brain Tumour Patient Advocates

Dr Normand Laperriere gave a thorough and accessible overview of the different types and phases of clinical trials. After an explanation of traditional approaches, he explored new, innovative approaches that are being rolled out with experimental brain tumour treatments.

Dr Laperriere first put participants at ease by stating that he is a lay doctor in epidemiology - medical statistics - and encouraged questions. Clinical trials are conventionally designed in phases - I, II and III - with each phase serving a different and important function that must be completed successfully before progressing to the next phase.

Phase I trials are designed to test the optimal dose of a new drug in human beings. Prior to this, a drug has been tested on animals. Phase I human trials are used to determine the dosing interval and route of drug delivery.

The most common phase I trial design involves three patients given a starting dose of an experimental drug. Then the dose is increased and given to three more patients. This pattern is continued until a third of patients experience unacceptable toxicities, at which point the trial is halted. From these results the dose limiting toxicities (DLTs) and the maximum tolerated dose (MTD) can be established. Patients enrolled on phase I trials of cancer treatments are often those with advanced tumours who have exhausted all available therapies. The next stage of a phase 1 trial is to test the new drug on a larger number

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Above: Dr Normand Laperriere (Canada) facilitates the IBTA masterclass on "What's New in Clinical Trial Design?"

Above: Masterclass formats – with small groups – enabled IBTA Summit participants to learn in an informal setting where questions, debate and discussion were encouraged by the masterclass facilitators. Pictured here is the masterclass on clinical trial designs.

of patients who have a specific tumour type. This might involve 30 or so patients with advanced cancers.

A phase II trial may enrol around 80 patients with a specific brain tumour (e.g. glioblastoma). Phase II trials are designed to assess the safety and efficacy of the drug.

Some terms commonly used in brain tumour trials are:

- 'partial response' which indicates a 50% tumour volume reduction on brain imaging
- tumour 'progression' meaning that the tumour has grown by at least 25%

Because there can be 10-20% variability in measurements due to differences in scanning angles, assessing response can be an imprecise science.

The usual endpoints for phase II trials are:

- response assessment
- progression-free survival (PFS)
- overall survival (OS)
- toxicity

But previous clinical trials of the drug bevacizumab (Avastin) in brain tumours have revealed the limitation of conventional response measures. In addition, some patients who received the therapy showed 'pseudo-progression' on brain scans which falsely gave the appearance of tumour growth as a result of actual tumour death.

A Phase III trial is the final stage of testing before a new drug can be approved as a safe and effective treatment and released onto the market. Phase III trials, also termed 'randomised controlled trials' (RCTs), represent the so-called 'gold standard' of drug testing. In these trials, two groups of patients with the same condition (e.g. glioblastoma) are randomly given either the new drug or an existing treatment. Five to six hundred patients are generally needed for phase III trials. These patients must be stratified according to their risk (e.g. by known prognostic factors, such as age) so that the two treatment groups contain people with equivalent starting prognoses.

When comparing the outcomes of the two groups of patients, overall survival is traditionally the best measure of a drug's effectiveness. Progression-free survival (the amount of time lived before the tumour grows) is not as good as a primary endpoint.

Toxicity (also termed 'adverse events') is recorded for individual patients on a five-point scale, where 5 is death, 4 is a potentially life-threatening toxicity, and 3 is a severe reaction. Any adverse event scored at 3 or above is considered significant. All phase III trials of brain tumour therapies now include measures of patient quality of life.

Two other clinical trial phases are less well-known.

Phase 0 trials precede phase I trials and are tests of the new drug at a low dose in a small number of people (10-15). This type of trial tests the drug's pharmacokinetics (how it travels through the body and is broken down).

Phase IV trials are those that take place when a drug is already on the market. These are often performed by analysing large numbers of patient records several years after the medicine's approval to look for rare side-effects or toxicities not detected in phase III.

The future of clinical trials

Conventional trial procedures have set protocols, number of patients and outcome measures. Their shortcoming is that they don't fully analyse the available results

Photos by MVF Studios

until all the data has been accrued. These limitations are particularly problematic for brain tumours, where gathering the required number of patients and meeting the pre-defined outcome measures can be very difficult.

Dr Laperriere said: "Adaptive trials started approximately around the year 2000 and are the way of the future. As the name suggests, these trials do not have rigid protocols, but can 'adapt' to patients' responses to treatment. Researchers can learn from the data as it emerges. They can alter the drug dose, and can drop or add an 'arm' (a cohort of people receiving a specific treatment regimen)."

The randomisation ratio can also be changed (or 'enriched') in an adaptive trial, so that more people can join a treatment arm if the therapy appears to be having a beneficial effect. Or a treatment arm can be dropped completely if it is proving ineffective. Adjustments can be made without needing to halt the trial and seek re-approval for a new protocol. Initiating a trial for a new drug is bureaucratic, expensive, and typically takes two to three years. The versatility of the adaptive trial design has both ethical benefits and is generally thought to be more efficient.

Rather than be restricted by the conventional phase I, II and III structure, an adaptive trial may move seamlessly from one phase to the next. For example, if a phase II trial is proving successful then the trial can continue into phase III while keeping the patients who are already enrolled on the trial. This is far more economical and spares a three-year lag between phases as well as saving the regulatory burden of gaining approval.

Why, therefore, aren't all trials adaptive?

Dr Laperriere explained that in the past, we didn't have all the molecular markers and prognostic indicators that we do now, so an adaptive trial focuses treatment on those who are most likely to respond.

"Adaptive trials have limitations, however. For example, the ability to shift patients away from treatments that appear to be ineffective may mean that long-term benefits could be missed," he said.

Dr Laperriere put the adaptive trial theory into context by running through various real-life clinical trial examples:

Example 1

Starting with the well-known 2005 phase III trial of temozolomide in glioblastoma led by Dr Roger Stupp and colleagues, Dr Laperiere showed the survival results of the study on a table and graph. Those who received temozolomide and radiotherapy in combination had an average overall survival of 14.6 months, compared to 12.1 months for patients who received radiotherapy alone.

At that time, it wasn't known that the status of the MGMT promoter gene in the tumour could have an effect on prognosis. But later analysis uncovered that temozolomide chemotherapy is most beneficial for patients whose tumours carry a methylated MGMT promoter gene.

Survival results from a clinical trial of elderly glioblastoma patients, published in 2017, supported this conclusion: the overall average benefit from temozolomide was three months – but in patients whose tumours carried an unmethylated MGMT promoter gene, temozolomide had no survival benefit at all. Dr Laperriere emphasised that it was lucky that the original Stupp trial had enrolled enough patients whose tumours happened to have a methylated MGMT promoter status for the benefit to be detected. "Otherwise, temozolomide might have been determined to be ineffective. This example thus demonstrates a limitation of not knowing the different individual factors that can affect prognosis. An adaptive trial design can make adjustments for known prognostic markers as they emerge, and make on-going alterations based on new discoveries."

Example 2

The next example Dr Laperriere discussed was of an adaptive clinical trial in breast cancer, which he said he chose because of its remarkably innovative and successful approach.

The I-SPY 2 trial commenced in 2011 and was designed to test potential chemotherapies administered after diagnosis but before first surgery. There are many different molecular markers (or 'signatures') in breast cancer that might influence prognosis and response to a given therapy.

Dr Laperriere described how the trial worked. "It would be a nightmare studying each breast cancer subgroup, even with the large number of breast cancer patients there are. Instead, the I-SPY 2 trial screened a sequence of 12 drugs, assigning each patient to a therapy based on the molecular profile that should theoretically have the most effect."

Dosages and drug type are fine-tuned throughout the study and each patient's findings used to inform how the next patient is treated. In this way, the researchers are able to hone in on effective treatments. So far, the trial is yielding positive results. I-SPY 2 has identified two

agents that appear effective enough to progress through to phase III testing (I-SPY 3). This pioneering trial is also remarkable because it is a collaborative effort between major public bodies such as the National Cancer Institute in the United States and the US Food and Drug Administration, as well as eight private pharmaceutical companies, 16 leading academic centres, the Safeway Foundation, and patient advocates.

Dr Laperriere presented other types of innovative clinical trials:

Basket trials test drugs that target a specific genetic mutation, irrespective of the cancer type, and enrol patients with various cancer types. Brain tumour patients whose tumour has a rare genetic mutation may be included in such a trial.

Umbrella trials focus on a specific cancer type such as glioblastoma,. Patients are stratified according to their biomarkers. INSIGhT and GBM AGILE are examples of brain tumour umbrella trials currently underway.

INSIGhT (INdividualized Screening trial of Innovative Glioblastoma Therapy) is a randomised phase II umbrella trial in newly diagnosed glioblastoma. The trial has four arms, with patients receiving either standard temozolomide and radiotherapy, or a regimen that includes one of four new agents. All patients are eligible for any of the treatments, but multiple interim analyses of results are performed to look for effects of the experimental drugs on specific biomarker/genetic tumour subgroups. The trial is also 'adaptive' because treatment arms can be stopped and new ones started when new drugs become available.

Dr Laperriere also briefly described **GBM AGILE** ("Adaptive, Global, Innovative Learning Environment"), which is an adaptive trial for glioblastoma that is currently in development. This is a phase II-III adaptive 'umbrella' trial that will test experimental drugs for various biomarkers in glioblastoma. The trial will take place in centres in the US, Canada, Europe and Australia/New Zealand.

Pediatric neuro-oncology: where are we today with treatment and where should we go tomorrow?

PROFESSOR RAKESH Jalali leads the Neuro-Oncology Group in Tata Memorial Hospital, Mumbai, India and he runs the Brain Tumour Foundation of India. He was also the driving force behind establishing the Indian Society of Neuro-Oncology (ISNO). He has a special interest in paediatric neuro-oncology.

Key points:

- Medulloblastoma is the most common primary malignant brain tumour in children, and has a survival rate considerably better than adult glioblastoma.
- Molecular and genetic advances have shown that medulloblastoma is not one, but four distinct diseases, each with its own prognosis and clinical behaviour.
- Therapies are being developed to target these individual subtypes.
- Much less is known about rarer childhood brain tumours, such as gliomas and pleomorphic xanthoastrocytoma (PXA), although molecular discoveries – such as the relevance of the BRAF gene in PXA – are opening opportunities for future therapies.
- There is a need to focus on survivorship in younger people – which is more than just living longer.
- Childhood brain tumours have high rates of long-term medical complications; intellectual decline is an almost universal consequence.
- Many researchers only focus on medical outcomes but the future needs to be on social endpoints – those things that matter to the individual, such as relationships, employment, and financial prospects.
- We have witnessed an evolution in brain tumour care, but there are vast discrepancies across the world. The international brain tumour community must come together to address these.

Above: Prof Rakesh Jalali: "Clinical trial researchers always need to realise that survivorship is more than simply surviving…Many trials still focus only on medical outcomes and tumour destruction. They neglect what matters to young people and their families, namely the probability of employment, personal relationships, financial and social independence, and long-term stability.

"This topic is very close to my heart," said Prof Jalali as he continued into his second talk about paediatric brain tumours.

"Brain tumours are the leading cause of death and disability in children and I want to tell you that as advocates and physicians, we need to impress on governments, the public and society at large, that it is quality of survival that is more important than length of life."

Prof Jalali explained that medulloblastoma is the commonest type of brain tumour in children. This type of tumour has a survival rate of 50-100% at two years, and 70-95% at five years. This is considerably better than glioblastoma (25-30% survival at two years, 10% survival at five years) which is the most common primary malignant brain tumour in adults. Compared to adult tumours, there is a lot of variability in paediatric medulloblastoma.

There are many complications of medulloblastoma, such as damage to mental faculties and hormonal dysfunction. There is a pressing need for robust risk stratification based on molecular profiling and clinical data so that treatment can be optimised for the individual child.

Medulloblastoma can be divided into average- and high-risk categories according to various features such as:

- the age of the patient
- whether there are secondary tumours (metastases)
- the appearance of the tumour under the microscope
- the tumour's molecular/genetic subgroup

The decision to treat should be based on a balance of risks. In children, the treatments themselves have a high risk of side-effects, which can have lasting impact on quality of life. The last ten years have seen a revolution in medulloblastoma diagnosis and care, thanks to advances in molecular profiling.

Medulloblastoma is not one, but four, distinct diseases based on an international consensus. These four groupings are:

- Wingless (WNT)
- Sonic Hedgehog (SHH)
- Group 3
- Group 4

These distinct groupings are of critical importance in the care of the paediatric patient. For example, WNT tumours carry a 95-100% survival, even if they have metastasised (seeded secondary tumours). To determine these groupings, molecular profiling must be done. This was previously expensive and lengthy, but because technology has developed to become faster and more affordable, techniques such as IHC (immunohistochemistry) make the process simpler and cheaper than ever before.

However, researchers are trying to find out whether it is possible to predict what medulloblastoma subgroup a tumour belongs to from an MRI scan thus potentially forgoing the need for surgery or biopsy. Prof Jalali referred to 2016 research, which showed that the size, position and appearance of a medulloblastoma on MRI was accurate for predicting SHH type in 95% of cases, while Group 4 could be predicted with 75% accuracy.

Prof Jalali also described recent and ongoing research taking place in the USA and India exploring how to de-escalate WNT medulloblastoma therapy so that children only receive the surgery, radiation and chemotherapy that is absolutely necessary.

"Most glioma brain tumours in children are low grade," said Prof Jalali. "Despite this term, paediatric glioma in certain situations, such as diffuse pontine gliomas, should never be considered benign because survival can be as low as 5-10% in these tumours. Before molecular profiling, paediatric gliomas were a confusing bag of pathologies, presenting with many different appearances on histology and MRI. However, the discovery that the BRAF gene is relevant to childhood glioma has greatly increased our understanding."

Using a case study of an eight-year-old boy diagnosed with a brain tumour after experiencing two months of

headaches and ataxia (loss of muscle co-ordination), Prof Jalali illustrated the importance of the BRAF gene. In this instance, the histology report suggested that it was an oligodendroglioma, but the presence of a BRAF fusion showed that it was actually a pilocytic astrocytoma which carries a better prognosis.

The BRAF gene may also prove to be important in treatment, Prof Jalali explained. "BRAF inhibitors are a class of drugs that have the potential to treat BRAF mutant tumours."

There are two types of BRAF mutations in brain tumours:

1. BRAF fusion - where two genes have joined together abnormally and which is diagnostic of pilocytic astrocytoma and

2. BRAF V600E mutation - usually found in ganglioglioma tumours and the rare pleomorphic xanthoastrocytoma (PXA)

Prof Jalali elaborated **on PXA tumours**, which are grade II gliomas seen in children and young adults, and the impact which the updated WHO classification and knowledge of the BRAF gene have on how the tumours are dealt with. The BRAF V600E mutation occurs in 50-60% of PXA tumours. When the updated WHO classification was applied to patients in the Tata Memorial Centre Hospital in Mumbai, India, several PXA patients had their diagnoses changed from grade II to grade III tumours.

Glioblastoma (GBM) in children is relatively rare (less than 5% of paediatric brain tumours) and – importantly – is biologically different to adult glioblastoma.

Paediatric GBMs do not have IDH mutations, have a poor prognosis, and there is no accepted standard treatment. Vaccine and immunotherapies are being investigated as potential treatments for this type of childhood brain tumour.

Another type of paediatric brain tumour, diffuse intrinsic pontine glioma (DIPG), has a very poor prognosis. Just 5-8% of children with DIPG survive two years. A mutation in the H3K27 gene is seen in 80% of cases. Targeted therapies are being investigated, informed by an increased understanding of this tumour's molecular and genetic characteristics.

Expanding on potential targeted therapies, Prof Jalali explained that manipulating the body's own natural killer (NK) immune cells to trigger them to attack tumour tissue offers some hope. This approach is the subject of current clinical investigations. Infusions of NK cells have been shown to maintain remissions in children with leukaemia.

CAR-T therapy uses a similar principle (with the T-cell class of immune cells) and has received much attention recently thanks to a brief report in the *New England Journal of Medicine* showing the effects of this treatment in glioblastoma patients. This new type of immunotherapy offers much potential for these hard-to-treat paediatric brain tumours.

The second part of Prof Jalali's presentation focussed on survivorship.

"It is the quality of a person's life that is of principle importance, rather than its length alone," he said.

He showed a photo of a medulloblastoma survivor giving an address from a podium at the Asian Society for Neuro Oncology (ASNO) Annual Meeting 2013. This confident young man was a living example of someone who was leading a normal/near-normal life after a high-risk medulloblastoma diagnosis which had even metastasised to his spine. He received a novel protocol of cranio-spinal radiation therapy (CSI) with carboplatin chemotherapy, and went on to complete his education and qualifications in business administration.

Childhood brain and spinal tumour survivors have a higher rate and severity of long- term medical consequences than those with leukaemia and most other cancers. The Childhood Cancer Survivor Study, which included over 10,000 individuals, revealed that 63% of childhood brain tumour survivors have at least one long-term medical condition, and 27% have an on-going medical condition that is severe or life threatening. Neuroendocrine (hormonal) dysfunction is a problem for many paediatric patients. This is a particular issue in the developing world, where replacement hormone therapy (e.g. growth hormone) is often not available.

Nearly all childhood brain tumour patients have some worsening of intellectual abilities, which is typically related to radiation therapy. This is most marked in the youngest patients, children from a low socio-economic background and those who have a supratentorial tumour (i.e. in the upper regions of the brain).

Strokes are also a common side effect of paediatric brain tumours and this risk increases with radiotherapy to the brain. Research, however, now shows that newer radiation therapy technologies (such as conformal/3D therapy) reduce radiation exposure to healthy brain tissue and have better outcomes.

Prof Jalali highlighted the unique challenges faced by adolescents and young people with brain tumours.

- Body image may be negatively affected.

- Fatigue can lead to reduced participation in sport/physical activities.
- There can be growth disturbances and hair loss.
- Weight gain can result.
- Fertility can be impaired
- Sexuality can be affected due to a dissatisfaction with the 'ideal self' and the perception of being rejected.

Has the evolution in brain tumour therapy improved survivorship?

Prof Jalali presented data showing that since the 1970s there has been a marked shift from radiotherapy that irradiates the whole brain toward more targeted radiation therapies, such as proton therapy. Research shows that one benefit from this change is that childhood patients treated with proton therapy are significantly less likely to experience secondary tumours (5.4% vs 8.6%).

"Clinical trial researchers always need to realise that survivorship is more than simply surviving," said Prof Jalali. "Imagine asking a parent what they consider most important for their child. What would they say? Many trials still focus only on medical outcomes and tumour destruction. They neglect what matters to young people and their families, namely the probability of employment, personal relationships, financial and social independence, and long-term stability. We should focus on these types of social endpoints."

Prof Jalali stressed that there are vast discrepancies in resources and survivorship between the developed and developing world. In brain tumour care, 95% of the world's resources are in the developed world. Hence the cure rate of childhood brain tumours is less than 30% in the developing nations compared to over 70% in the developed world.

There are some sobering statistics:

- In Japan there is one neurosurgeon for every 50,000 people while in Bangladesh there is just one neurosurgeon per 3.6 million people.
- Eighty-five per cent of the world's population is in developing nations and, with eight million new cancer patients per year in these countries, there is a current shortage of 5,000 radiotherapy units. Presently there are just 4,400 in the developing world.

Prof Jalali is working with The Brain Tumour Foundation of India (which he established) to improve access to modern brain tumour care in his country. "We all have a role to play. We must come together globally to ensure that every child has the best possible therapy."

Key points from two of the other plenary sessions at the IBTA's third biennial World Summit of Brain Tumour Patient Advocates

State of the art: radiation treatments

DR NORMAND LAPERRIERE is Head of Ocular Oncology at Princess Margaret Cancer Centre, Canada, and Professor in the Department of Radiation Oncology at the University of Toronto.

Key points:

- Great advances have been made in recent years, but radiation therapy is often seen as a mysterious 'black box'.
- Beams of radiation can now be formed into the three-dimensional shape of a tumour, minimising damage to surrounding healthy brain tissue.
- Improvements in imaging technology mean that contouring of brain tumours can be performed more accurately than before, and in three dimensions.
- MRI and CT imaging play an important role in modern radiation therapy regimens.
- Even low-tech solutions, such as DVD players used to play their favourite music, have improved young patients' experience of radiotherapy.
- Daily CT scanning during radiotherapy allows for ongoing dosing changes and adjustments, improving accuracy and lessening side effects.

State of the art: systemic treatments

DR MARK GILBERT is Chief of the Neuro-Oncology Branch at the National Institutes of Health (NIH) in the USA. An expert in clinical malignant glioma research, he gave a whistle-stop tour of advances and revelations in the systemic treatment of primary malignant brain tumours.

Key points:

- Molecular testing has revolutionised our understanding of brain tumour types, revealing hitherto unknown classifications of brain tumours – each with their own clinical behaviour.
- Discovering the role of the IDH genes – which correlates with a better prognosis when mutated – has been critical in this advancement, revealing how the microscope (histological) appearances of tumour tissue alone are no longer sufficient for categorising brain tumours.
- Studies have shown that the molecular signature of a tumour can serve to guide treatment and predict prognosis.
- The discovery in 2005 that temozolomide chemotherapy significantly improves survival in glioblastoma was a watershed moment in brain tumour therapy, and highlights the importance of well-controlled randomised trials for testing new treatments.
- The first trials of PCV chemotherapy in newly diagnosed anaplastic oligodendroglioma showed no benefit, but later analysis based on genetic mutations in the tumours revealed that the therapy does indeed have a significant effect on tumours with a specific genetic mutation (deletion of the 1p/19q chromosome segments).
- Bevacizumab (Avastin) showed short-term benefit in glioblastoma in early clinical trials, leading to its accelerated approval by the US Food and Drug Administration (FDA). Subsequent analysis revealed that it did not improve overall survival, further highlighting the importance of thorough clinical testing of new agents.
- Immunotherapies are an exciting, new brain tumour treatment approach, and many of these – which can be divided into 'classic' and 'neo-classic' approaches – are under investigation.
- Although data from several phase 2 trials of an anti-EGFRviii vaccine (a type of immunotherapy) provided early suggestions that the treatment is effective in this subset of malignant brain tumour patients, a subsequent large, randomized clinical trial failed to show benefit, highlighting the need to confirm early findings.
- A dendritic cell vaccine (DCVax) has shown promising results in early clinical trials, although well-conducted phase 3 trials are called for before drawing definitive conclusions.
- There can be pitfalls in clinical trials of immunotherapy - as was demonstrated in a trial of the checkpoint inhibitor nivolumab - which can lead to 'pseudo-progression', an apparent worsening of a brain tumour on scans despite destruction of the tumour

To read the free access 2018 World Summit of Brain Tumour Patient Advocates Report in full online, please visit **https://issuu.com/ibta-org/docs/summit_report_2017**

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Meningioma UK www.meningiomauk.org
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MeningiomaUK
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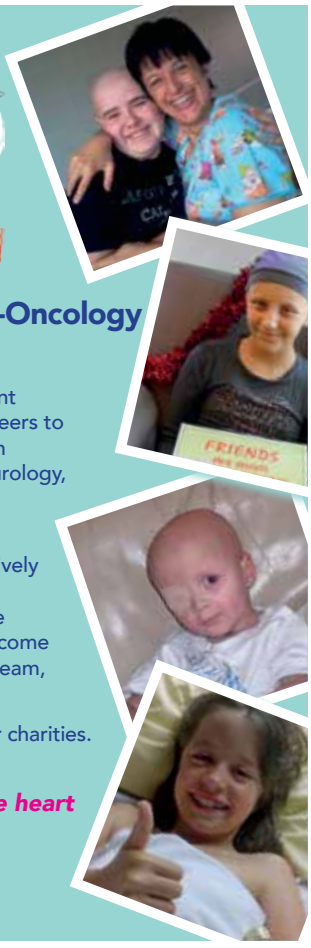

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ZIMBABWE BRAIN TUMOUR ASSOCIATION

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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

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Achieving Through Hope & Strength

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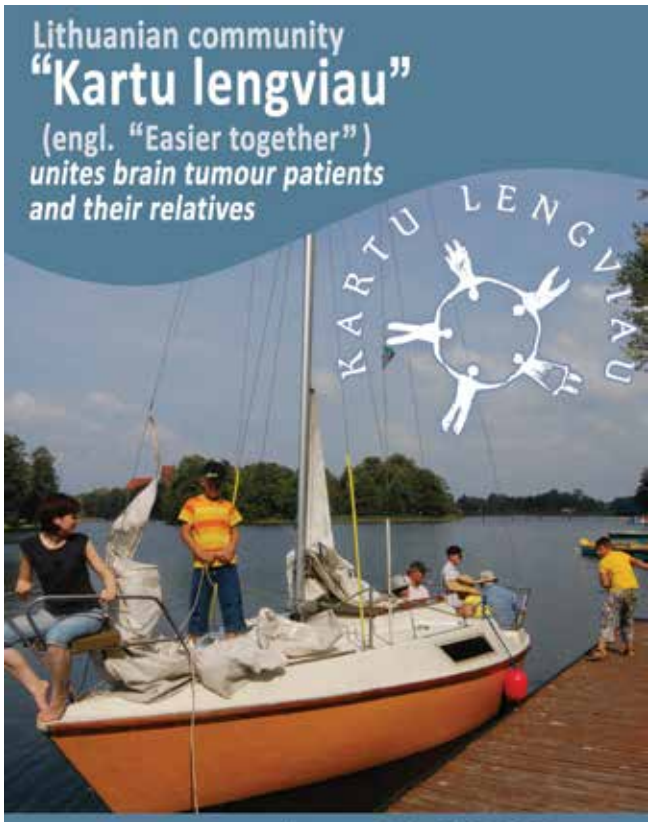

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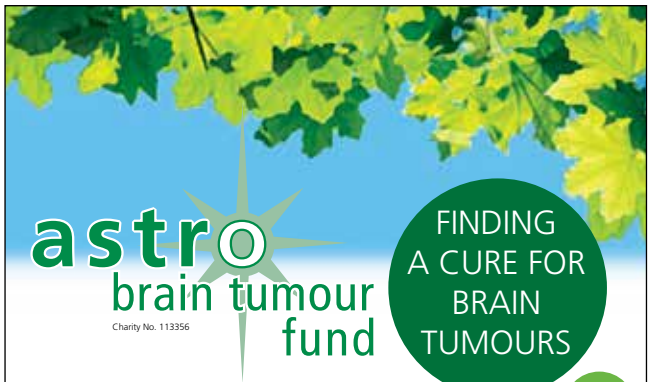

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GFME 15 years

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 **650 patients,** care givers**, friends and family members** around the globe. For more details gfme@free.fr

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/

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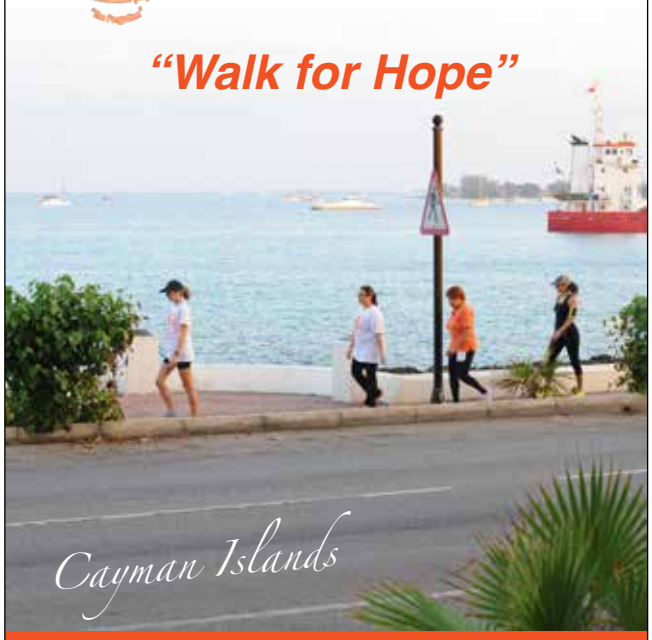

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Brain Tumour Foundation Cayman Islands "The Forgotten"
Ph: (345) 916 1811 - Fax: (345) 947 5518

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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

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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

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/

Joe di Palma Brain Tumor Foundation
www.joedipalmafoundation.com

Meagan's Walk:
Creating a Circle of Hope
www.meaganswalk.com

Tali's Fund
www.taldoron.com

CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands)
"The Forgotten"
http://www.btfcaymanislands.com

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/

EL SALVADOR

Gris Positivo
http://grispositivo.org

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

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/

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

NETHERLANDS

Hersentletsel.nl
http://www.hersenletsel.nl

Hersentumor.nl
http://hersentumor.nl/

STOPhersentumoren.nl
www.stophersentumoren.nl

NORWAY

Hjernesvulstforeningen
www.hjernesvulst.no

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

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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

BT Buddies
www.btbuddies.org.uk

Charlie's Challenge
www.charlieschallenge.com

Clowns in the Sky
http://www.clownsinthesky.org/

East Kent Brain Tumour Support Group
https://www.facebook.com/EKBTSG/

Ed Evans Foundation
www.edevansfoundation.co.uk

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/

Meningioma UK
www.meningiomauk.org

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

Accelerate Brain Cancer Cure
www.abc2.org

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
http://dccc.convio.net/site/PageServer?pagename=angels_home

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 Foundation for Children
www.braintumorkids.org

Brain Tumor Fund for the Carolinas
http://www.btfcnc.org/about/overview.cfm

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

Charles Warren
Brain Tumor Awareness Foundation
www.charleswarrenfoundation.org

Childhood Brain Tumor Foundation
www.childhoodbraintumor.org

Children's Brain Tumor Foundation
www.cbtf.org

Chordoma Foundation
http://www.chordomafoundation.org

Chris Elliott Fund/
EndBrainCancer Initiative
www.chriselliottfund.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

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/

Legacy Brain Foundation
http://www.legacybrainfoundation.com/

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
http://www.roconnow.com/

San Diego Brain Tumor Foundation
www.sdbtf.org

Sontag Foundation and Brain Tumor Network
(BTN)
https://sontagfoundation.org
http://www.braintumornetwork.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

Walk for Kate and Blankets for Brains
http://www.walkforkate.org/about.html

We Can
Pediatric Brain Tumor Network
www.wecan.cc/We_Can/Home.html

Western North Carolina Brain Tumour Support
www.wncbraintumor.org

ZIMBABWE

Zimbabwe Brain Tumor Association (ZBTA)
https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/

INTERNATIONAL BRAIN TUMOUR ALLIANCE

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and the

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1 January - 31 December 2018

20 - 27 October 2018

The IBTA requires no financial commitment from your organisation to be a supporter.
Contact **kathy@theibta.org**

YOUR SUPPORT OF THESE TWO POPULAR GLOBAL EVENTS WILL FURTHER HELP BRAIN TUMOUR PATIENTS TO DEAL WITH THE CHALLENGES THEY FACE.

BRAIN TUMOURS

URGENTLY NEEDED:

MORE RESEARCH AND SUPPORT

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