

Brain Tumour

You are not alone on this journey...

**Inside: the “Brilliance!”
2021 virtual exhibition
catalogue of creative
works from the global
brain tumour community**

■ **The Ocean and Sky
Children’s Hospice
in Yokohama, Japan**

PLUS: Stories from our
international brain tumour
community in: Denmark,
United States, Austria, Italy,
Canada, India, New Zealand

■ **The brain tumour and
cancer communities rally
for Ukrainian patients**

■ **Supporting the patient
voice in HTA**

■ **IBTA
podcast -
A Brain Tumour
and Me**

■ **OPTIMUM –
a new study
of recurrent
low grade
glioma**

**Our cover
story:**

**The PVW Brain
Tumour Foundation’s
Hong Kong awareness
walk: COVID-style**





International Brain Tumour Awareness Week 2022

The 2022 International Brain Tumour Awareness Week
will take place from Saturday, 29th October
to Saturday, 5th November 2022

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

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

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

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VARIATIONS IN SPELLING

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

Dear Friends,

As the world began to emerge from the COVID-19 pandemic earlier this year, our attention and efforts at the IBTA were refocussed on the catastrophic situation in Ukraine and the effect of the war there on Ukrainian citizens with brain tumours and other cancers. As one of our Ukrainian patient advocacy colleagues told us, Ukrainian cancer patients face two substantial challenges - surviving a brutal war and surviving their cancer. At the time of publishing this magazine, and according to the World Health Organisation (WHO), over 300 attacks had taken place on healthcare in Ukraine, including health facilities, transport, personnel, patients, supplies and warehouses. In this edition of *Brain Tumour* magazine, we share news of an initiative from the European Cancer Organisation and ASCO Special Network addressing the effects of the war in Ukraine on cancer, including brain tumours.

Also in this issue we look at a wide range of other news from the international pediatric and adult brain tumour community. We are also proud to reproduce in this year's magazine, the entire catalogue for the IBTA's "Brilliance!" virtual art exhibition which we launched in 2021 and which shines a bright, uplifting light on the talents of those in the international brain tumour community, sharing a little bit more of who we are, beyond the impact of a brain tumour in our lives.

As always, we trust that the articles in this magazine bring to our community a sense of collaboration, progress, camaraderie and, of course, hope.



With best wishes,

Kathy Oliver

Chair, International Brain Tumour Alliance (IBTA)

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



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Meet the IBTA team



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Around the World with the IBTA

The IBTA has contacts in 113 countries around the world to whom it makes available its free annual magazine, *Brain Tumour*.

We print between 10,000 and 14,000 copies of *Brain Tumour* magazine each year and send them for free to recipients

in these countries. We also publish the magazine digitally on www.issuu.com

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

Brain Tumour magazine has readers in the following countries:

Afghanistan ■ Albania ■ Algeria ■ Argentina ■ Australia ■ Austria ■ Bangladesh ■ Belarus ■ Belgium ■ Bolivia
Bosnia-Herzegovina ■ Brazil ■ Bulgaria ■ Cameroon ■ Canada ■ Chile ■ China ■ Colombia ■ Congo ■ 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
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Past editions of *Brain Tumour* magazine are available online here:

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The Cancer Community Rallies for Ukrainian Patients

ECO Communication Team
European Cancer Organisation (ECO)



Professor Andreas Charalambous, President of the European Cancer Organisation (ECO) and Co-chair of the Special Network on Ukraine



Dr. Eric Winer, President of the American Society of Clinical Oncology (ASCO) and Co-chair of the Special Network on Ukraine



Richard Sullivan, MD, PhD, Director of the Institute of Cancer Policy at King's College, London, UK, and Key Advisor to the Special Network on Ukraine

In a country engulfed in so much death and destruction, it can be easy to forget the unique challenges faced by cancer patients in Ukraine.

Russia's unprovoked and indiscriminate attacks have not only left many of these patients homeless, they have destroyed clinics and hospitals that provide essential cancer care.

"We realise that everyone in Ukraine is struggling to survive this horror," said Prof. Andreas Charalambous, President of the European Cancer Organisation (ECO). "But cancer patients face an inescapable truth: their disease will not wait for the shelling to stop. They need treatment now."

The Special Network on the Impact of the War in Ukraine on Cancer

So, with a palpable sense of urgency, ECO with other cancer and health focused international societies banded together to



create the Special Network on the Impact of War in Ukraine on Cancer.

"The ECO Board of Directors took this initiative just a week-and-a-half after the invasion began," said Prof. Charalambous, a Co-chair of the Special Network. "We were unanimous. This is the priority of a lifetime in oncology."

ECO teamed up with the American Society of Clinical Oncology (ASCO), the World Health Organization (WHO), and the European Commission to share intelligence and launch advocacy efforts. Today, the network includes representatives from more than 300



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"...cancer patients face an inescapable truth: their disease will not wait for the shelling to stop. They need treatment now."

Prof Andreas Charalambous, President, European Cancer Organisation



cancer organisations around the world, including inspirational patient organisations, many from within ECO's Patient Advisory Committee, who have acted with the immediacy needed to identify vulnerable groups on the ground and direct them to the safety, support, and treatment they deserve.

While governmental institutions may have the resources, it is the patient organisations working in partnership that help inform exactly which, where, and when resources are needed. With this bottom-up approach, it is accurate to say that patient organisations have been, and continue to be, a guiding light during this crisis.

"Almost immediately our ECO partners saw a need for a coordinated response and approached ASCO to be a part of the solution, and we're grateful that they did," said Dr. Eric Winer, President of ASCO and a Co-chair of the Special Network. "The humanitarian crisis from the war in Ukraine, even within just the cancer space, is large, complex, dynamic, and multifaceted. This clearly requires a multifaceted response... and just as important, this multifaceted response needs open communication and coordination, and a sharing of intel of what is happening and what is needed. Bringing

"The humanitarian crisis from the war in Ukraine, even within just the cancer space, is large, complex, dynamic, and multifaceted."

Dr Eric Winer, ASCO President

groups together and helping to coordinate their efforts – that is the role of the Special Network."

The role of the Special Network

The network's most visible contribution has been the creation of the patient website, www.onco-help.org. Here, Ukrainian cancer patients can discover an array of specific resources for those remaining in Ukraine or fleeing to any of 30 other European countries. More country categories and related content continue to be added to the website.

In multiple languages, the website identifies which cancer centres are offering which treatments (with contacts and locations), and which medical protocols should be continued inside Ukraine and which ones can be easily administered elsewhere. There are separate sections on paediatric oncology facilities, general medical services, and psycho-social support. The goal is to link those who need help with those who want to help. Ukraine, Poland, and Germany are currently the most accessed country pages.

"This [war in Ukraine] requires a mid-level network to effectively interface with both the ground and with high politics, which is where the Special Network has fitted in."

Richard Sullivan, Director,
Institute of Cancer Policy

According to the WHO, most Ukrainian cancer patients currently undergoing active cancer treatment are still in Ukraine, and the Special Network is working to identify the specific resource needs of those centres, especially medications and surgical supply shortages. Of the Ukrainian patients being treated outside of Ukraine, the network is gathering data on capacity issues.

Detailed information gathering is crucial

The information being collected and collated by the network is an intelligence lifeline for the WHO and the European Union, according to Richard Sullivan, MD, PhD, Director of the Institute of Cancer Policy at King's College, London, and Key Advisor to the Special Network.

"By reason of politics, size and/or legislation," he said, "government and UN agencies have always had three major issues: the speed in which they could react, the distance from ground reality, and the ability to adapt to rapidly changing situations. This requires a mid-level network to effectively interface with both the ground and with high politics, which is where the Special Network has fitted in."

Looking to the future

It is a role the Special Network may be playing well into the future. At the time of writing this article (4 July 2022), the WHO says Russia's invasion has already resulted in over eight million refugees fleeing to other countries, over six million internally displaced people, and 323 attacks on health care.

"Even if the war were to stop tomorrow," said Prof. Charalambous, "it would take a year or two, at least, to rebuild cancer care there."

For the European Cancer Organisation, the message is clear: everything humanly possible must be done to ensure Ukrainian patients can get appropriate cancer treatment where needed, when needed. ■

Any organisation wishing to join the Special Network should send an email to ukraine@europeanccancer.org. Efforts to promote the website www.onco-help.org would be greatly appreciated.

Ukrainian brain tumour patients and the IBTA



The war in Ukraine has been cataclysmic for healthcare in that country.

At the time of this magazine's publication, over eight million Ukrainians were refugees and over six million Ukrainian citizens were internally displaced in their country. That's over 14 million people out of a population of 43.2 million.

At the time of writing, the World Health Organisation (WHO) reports that there have been 323 attacks on healthcare in Ukraine, including "health facilities, transport, personnel, patients, supplies and warehouses" (Emergency in Ukraine: external situation report #16, published 30 June 2022: reporting period: 16–29 June 2022). So Ukrainian brain tumour patients face two enormous challenges – surviving a brutal war and surviving a brutal cancer.

For the first months of the war in Ukraine, it largely fell to patient advocacy organisations to fill a gaping hole in the rescue and relocation of Ukrainian refugees with cancer. As patient organisations, our priority was to quickly get cancer patients out of Ukraine and into safe-haven countries to continue their cancer treatment.

During the first weeks of the war in Ukraine, the IBTA met online first thing every morning with European and international patient advocacy organisations representing blood cancers, breast cancer, kidney cancer, melanoma, myeloma and other site-specific cancers. We exchanged information about safe corridors out of Ukraine and treatment possibilities in the bordering countries of Poland, Hungary, Romania, Slovakia and Moldova. We also worked with our clinical contacts to place patients in European

healthcare institutions outside of Ukraine.

And we worked with incredibly brave people - whose names we never even knew - who were literally dodging snipers and bombs, extracting cancer patients from war zones in the eastern part of Ukraine and transporting them to safety.

Many refugees have fled Ukraine without any medical records. Or their medical records were destroyed by bombing. Ukrainian cancer patients and their families are also suffering from substantial trauma and are in great need of psychological support. The language barrier is significant and we had to quickly line up numerous translators to help us.

At the IBTA, we created a resources page for Ukrainian brain tumour patients on our website, and also a help form which patients can fill in quickly online. These website pages are available in Ukrainian and English. We're also working very closely with the European Cancer Organisation (ECO) and American Society of Clinical Oncology (ASCO) as part of their Special Network on Ukraine. This Network, in turn, provides a direct channel of communication with the European Commission, WHO, Union for International Cancer Control (UICC) and oncologists in Ukraine.

So far at the IBTA, we've helped an anaplastic meningioma patient in central Ukraine (with the great assistance of our Polish colleague at the Glioma Foundation Center); a newly diagnosed glioblastoma patient who fled to Romania; an adult patient with an anaplastic oligodendroglioma; an adult patient with a medulloblastoma, and a two-year-old child

who actually turned out not to have a brain tumour but a previously undiagnosed very rare neurological condition. The IBTA helped the child and the family get a correct diagnosis in Germany.

Although we've dealt with a small number of brain tumour patients from Ukraine up to now (we anticipate more will come), each case has been extremely complex. Some of the cases involve working with other organisations which arrange "extraction" from eastern Ukraine, transportation through safe corridors and accommodation in the new host country. We help organise brain tumour treatment outside of Ukraine working with advocacy colleagues and clinical contacts - for example - in Poland, Romania and Italy.

The enormous initial wave of Ukrainian refugees crossing borders has wound down from those first frenetic months. But the situation in Ukraine is still highly volatile and unpredictable. Peace and reconstruction seem a very long way away. But one day re-building will start, and we should be thinking now of how we, as the international brain tumour community, can continue helping Ukrainian brain tumour patients, their families and healthcare professionals during that rebuilding stage. ■

For more information on the IBTA's work with Ukrainian brain tumour patients, see <https://theibta.org/ukraine/>

onco-help.org

Information hub signposting healthcare professionals and Ukrainian cancer patients to real-time information and contacts – across multiple languages, inside Ukraine and throughout much of Europe.

Contribute to its development:
If you are aware of other useful resources, contact us at ukraine@europeancancer.org



An initiative by:



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Zorg mee voor een betere toekomst door uw nalatenschap door te laten leven in onze onderzoekprojecten. Uw testament kan levens redden.

www. Hersentumoren.nl Stichting

The Society for Neuro-Oncology Launches Virtual Pediatric Molecular Tumor Board Series

Shelley Pressley, MBA, CMP, Director of Administration
Society for Neuro-Oncology



There has been an explosion of knowledge regarding the biological nature of brain tumors arising in infants, children, and the adolescent and young adult (AYA) population over the last ten to fifteen years, with an increasing number of molecular types and sub-types of brain tumors being recognized. As historical brain tumor diagnoses are now being refined and replaced with new molecular types of brain tumors, molecularly annotated clinical data to inform the best standard of care therapy, particularly for more rare types of tumors, are critically lacking.

Thus, the prescribed therapy for patients, with the same rare tumor histology, can often vary depending on the treating institutions or region of the world, making

direct comparisons and establishing uniform medical patient management guidelines challenging. Based on age at diagnosis and location of the tumor, even the more common pediatric central nervous system (CNS) tumors can present unique surgical and medical challenges, requiring the need for complex multi-disciplinary care to achieve best patient outcomes. Furthermore, with improved molecular knowledge, has come an increasing cadre of novel targeted therapies that a pediatric brain tumor doctor needs to keep in their armamentarium.

SNO's Pediatric Molecular Tumor Board Series

With the intent to "learn from every child with a brain tumor diagnosis,

anywhere in the world", the Society for Neuro-Oncology (SNO) Pediatric Special Interest Track has launched the Pediatric Molecular Tumor Board Series with the objective to advance education on clinical management of pediatric brain tumor patients in the molecular era. The SNO Tumor Board aims have been created to provide a live forum to share clinical expertise and patient-based experiences by bringing together multi-disciplinary clinical experts in pediatric diagnostic imaging, pathology, surgery, radiation oncology, medical oncology and clinical scientists. These specialists participate in an in-depth round-table discussion on all aspects of patient care, including medical approaches, use of conventional and ➤



SNO Board member and Pediatric Track co-lead, Annie Huang, MD, PhD



Junior tumor board co-chair, Craig Erker, MD, MS



Junior tumor board co-chair, Holly Lindsay, MD, MS

novel treatment options based on current clinical and scientific evidence, with a particular focus on challenging pediatric and AYA brain tumor diagnoses.

Beyond clinical education, the tumor board aims to improve clinical and translational collaborative dialogue in the global pediatric neuro-oncology community and provide insights and opportunities to facilitate basic, translational, and clinical research. It is hoped that such collaborative efforts will fast-track tangible advances in medical management of pediatric brain tumor patients across the world including low and middle income and under-resourced countries.

Leadership and reach

The SNO Pediatric Molecular Tumor Board, is led by SNO Board member and Pediatric Track co-lead, Annie Huang, MD, PhD (SickKids Hospital, Toronto, Canada), with junior tumor board co-chairs, Craig Erker, MD, MS, (Dalhousie and IWK Health Center, Nova Scotia, Canada) and Holly Lindsay, MD, MS (Baylor College of Medicine and Texas Children's Hospital Cancer Center) and administered by SNO's support team, Chas Haynes, JD, Executive Director; Shelley Pressley, MBA, CMP, Director of Administration; and Melesa Ritterhouse, RN, CME and Academy Manager.

To date, the SNO Pediatric Molecular Tumor Board Series has reached over 2,000 neuro-oncology professionals from 41 countries. The success of this unique global collaborative tumor board launched

by SNO, has been due to the quality of the cases presented and the deep expertise of the multi-disciplinary expert panelists from around the world who are invited to present and share their patient cases and expertise. The proceedings of the Tumor Board are specifically designed to deliver dialogue that will enable participants at all levels of training and pediatric neuro-oncology practice experience from small and large institutions worldwide, to gain an understanding of current cutting-edge biological and clinical knowledge that can help guide their day-to-day management of difficult cases.

Virtual Participation

The typical audience for the SNO Pediatric Molecular Tumor Board Series includes clinical trainees, allied health professionals, patients and family members, and pediatric subspecialties in oncology, neuro-oncology, neurology, radiology, radiation oncology, pathology, and surgery. Registration is complimentary and limited to the first 1,000 participants. Real-life pediatric molecular tumor board cases that have been presented to date include the following:

- A six-month-old infant with a suprasellar embryonal tumor: diagnostics, management, and challenges
- NTRK mutant gliomas: diagnosis and management
- Embryonal tumor with multilayered rosettes (ETMR): evidence-based

recommendations for the diagnosis and treatment of this biologically and clinically heterogeneous pediatric CNS tumor

- Posterior fossa ependymoma: current upfront and relapse management strategies in the molecular era.

All pediatric molecular tumor board cases are recorded, so if you miss one, you will be able to view it on-demand on the Neuro-Oncology Academy website at www.neuro-onc.academy.org and select the category Pediatric Neuro-Onc.

Invitation to Submit a Case

The Pediatric Special Interest Track selects cases on rare and high-risk tumors to be presented on the tumor board and invites expert panelists to discuss the best treatment plans for the patients.

Selected cases must have relevance to a wide array of practitioners, including a minimum of three of the following: neuro-oncologists (pediatric/adult), neuropathologists, neurosurgeons, neuroradiologists, radiation oncologists, and trainees. Each selected case should highlight key challenges in either tumor diagnosis or treatment or both. Newly diagnosed and relapsed cases are welcome for submission. Each selected case should highlight opportunities for further research in either basic, translational, or clinical areas.

All members caring for the patient presented at the Pediatric Molecular Tumor Board from the local site (primary patient care team) are specifically invited to the

webinar and encouraged to participate. Invitations for viewing the tumor board will be disseminated through SNO, and participation is encouraged. ■

Neuro-oncology professionals interested in submitting a challenging case to be considered for a future broadcast of the Pediatric Molecular Tumor Board, should complete the online form which can be found at <https://neuro-onc-academy.org/content/pedstumorboard>. For more information about the Pediatric Molecular Tumor Board, please email pedstumorboard@soc-neuro-onc.org.

SNO and participants of the Pediatric Molecular Tumor Board accept no responsibility for the harms or benefits of patient disease-related outcomes of the presented subjects. The primary doctor remains responsible for all patient-related care and outcomes.

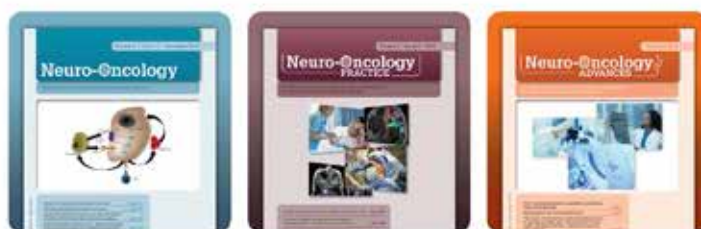


Raise awareness of the challenges
of brain tumours - plan an event for
International Brain Tumour Awareness Week 2022
(29th October to 5th November)

Save the date for
Tampa!

27th SNO
Annual Meeting
& Education Day
Tampa Convention Cntr.
November 16-20, 2022

SNO
Society for NeuroOncology



The Society for Neuro-Oncology exists to
advance multi-disciplinary brain tumor research,
education, and collaboration to drive discovery
and improve patient care.

For more information, visit:

www.soc-neuro-onc.org

Supporting the patient voice in HTA - launching a standard template for information

Kate Morgan, Head of Policy and Access

Myeloma Patients Europe

and Martin Coombes, Director, Policy Advocacy and Government Affairs

Bristol Myers Squibb

Patient involvement in HTA

Health technology assessment (HTA) is a critical part of securing access to new treatments for patients in many countries. It is an evidence-based process that is used by healthcare systems to determine the value of a new medical treatment or device.

It is increasingly recognised that HTA bodies should seek direct input from patients, their families and carers, although this does not always happen consistently. The views and experiences of patients and carers of what it is like to live with a condition, and the potential impact of a new treatment, is unique and provides a real-world perspective otherwise missing from HTA assessment. Engaging with patients, carers and patient advocacy organisations ("patient experts") to seek these insights should be a core part of an effective HTA process and there are many best practice examples of how this should be done effectively. For example, HTA bodies like the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) in the UK provide systematic written and verbal opportunities for patient experts to provide evidence.

To be involved in the HTA process, patient experts need clear and accessible information on the treatment and decision-making problem they are being asked to comment on. For example, it is useful to receive lay language information on the relevant clinical trial, treatment side-effects and how the treatment will be used in clinical practice. However, this information is not often available or accessible to patient experts. In addition, where information



HTAi PCIG SIP working group co-chair Kate Morgan, Head of Policy and Access, Myeloma Patients Europe

is provided by the HTA body it is often complex and technical in nature. Patient experts often have varying knowledge and experience of HTA, and the medical information being assessed. Taken all together, these factors mean participation is often difficult, which can impact on patient expert HTA submissions.

HTAi PCIG

Health Technology Assessment International (HTAi) is a global professional society for stakeholders who produce, use, or are involved in HTA. HTAi have an Interest Group for Patient and Citizen Involvement (PCIG) who share best practice, run projects, and develop tools that encourage robust engagement of patient experts in HTA.

To improve the quality of information provision to patient experts during



HTAi PCIG SIP working group co-chair Martin Coombes, Director, Policy Advocacy and Government Affairs, Bristol Myers Squibb

assessments, the PCIG developed a tool called the International Summary of Information for Patient Groups (SIP) template, alongside detailed guidance to support implementation by HTA bodies and the pharmaceutical industry. The idea is that this can be adapted and used by any HTA body in the world to support patient expert involvement.

What is the International SIP?

The International SIP is a plain language summary of an industry submission on a treatment that can be used by patient experts to inform their contribution to the HTA process. The submitting manufacturer completes the template, as part of their normal HTA submission, which is then reviewed by the HTA body before being shared with patient groups.

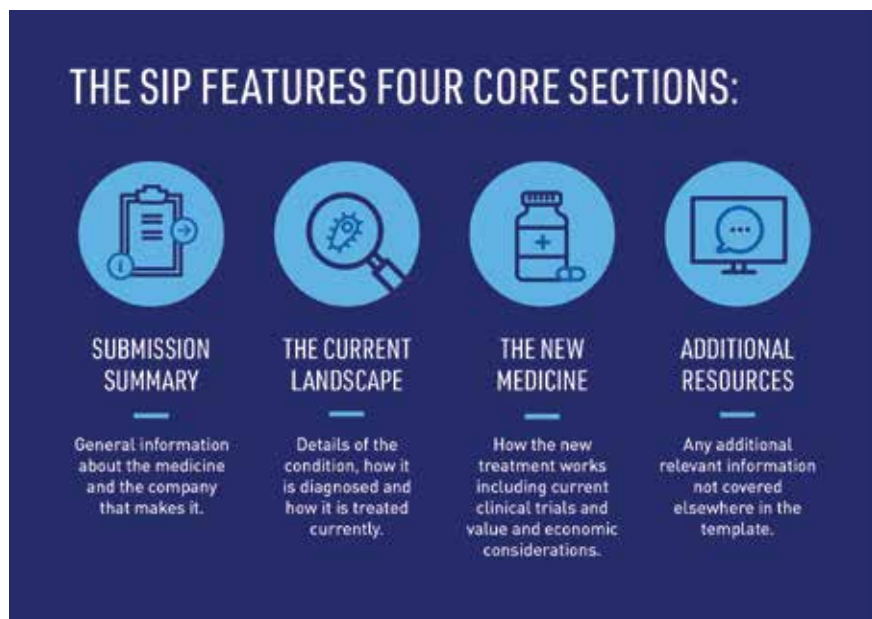


Figure 1: The four core sections of the SIP

The information contained in the SIP (see Figure 1) is intended to help patient experts to make informed contributions at the appropriate points in the HTA assessment process. This could be to support written submissions or in-person engagement and evidence sessions. The hope is that having a standard template and approach will ensure that patient experts have a baseline level of information and knowledge and that ultimately, this will lead to better informed patient expert contributions.

Experience of the SIP so far

The SIP approach was initially developed by the SMC and has become a standard part of their HTA submission process. A survey with 17 SMC patient experts who had received and read a SIP found the information helpful to formulating their response (see Figure 2 and Figure 3). This highlights the utility of the approach to some patient and carer experts, although others stated they preferred to conduct their own research.



Figure 2: How helpful was the SIP for patient experts?

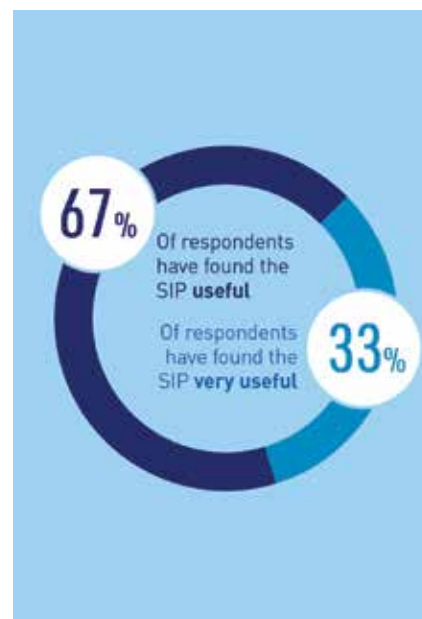


Figure 3: All of the SMC patient experts surveyed found the SIP to be either “useful” or “very useful”

Alongside other patient involvement initiatives, the SIP approach can be credited with improving the number and quality of submissions to the SMC from patient experts.

To create the international SIP and guidance, the PCIG project group used the SMC SIP template as a baseline and adapted it using the feedback of SMC users, European and international patient organisations, HTA representatives and the pharmaceutical industry. The template and guidance created has since been piloted by NICE and the Pharmaceutical Benefits Advisory Committee (PBAC) in Australia. The results of these pilots are currently being analysed to identify clear recommendations for other stakeholders wishing to adapt the approach.

Where next with the International SIP?

Given the obvious benefits, HTAi PCIG has created a further project group tasked with dissemination and communication of the International SIP. This multistakeholder group is working to identify and collaborate with select HTA bodies to assess whether the International SIP could work as part of their HTA process and, if so, how. Issues the group will be considering include the current patient involvement process, local context and resourcing requirements. It will also consider patient group perspectives in these countries and how the template and guidance could be further adapted to support implementation. ➤

Across countries, there are sometimes barriers, or perceived barriers, in place impacting on the dissemination of the SIP approach, such as the perception of bias of industry providing information to patient experts – which can be overcome by the HTA body reviewing the SIP before distribution. In addition, there are concerns about the capacity and resources of HTA bodies to review completed SIPs. These are issues that have been addressed both by the SMC and in the pilots, so we aim to disseminate best practice in this regard and work to develop further solutions to highlighted barriers.

Finally, as well as focusing on specific countries, the project group will also engage international, European and national patient organisations (and other stakeholders) in the work, informing them about the approach and seeking their insights and perspectives. ■

More information about the International Summary of Information for Patient Groups (SIP)

If you would like further information about the project or to get involved please contact the HTAi PCIG SIP working group co-chairs Kate Morgan, Head of Policy and Access, Myeloma Patients Europe on morgan@mpeurope.org or Martin Coombes, Director, Policy Advocacy and Government Affairs, Bristol Myers Squibb on martin.coombes@bms.com.

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

What's new?

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The IBTA also publishes a monthly e-News containing information of interest to our international brain tumour community such as treatment advances, cutting edge research, patient organisation news, industry news relevant to brain tumours and a listing of forthcoming conferences and meetings.

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- Gliosarcoma
- Medulloblastoma
- Meningioma (High Grade)
- Oligodendroglioma, Anaplastic Oligodendroglioma, and IDH-mutated Glioma
- Pineal Region Tumors
- Pleomorphic Xanthoastrocytoma (PXA), Anaplastic Pleomorphic Xanthoastrocytoma (APXA), and BRAF-altered tumors
- Primitive Neuro-Ectodermal Tumors (PNET)

Contact us at NCICONNECT@mail.nih.gov or (240) 760-6530.

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Temporal muscle thickness: a new prognostic marker in glioblastoma patients

Julia Furtner, MD, PhD, MBA, Associate Professor

Department of Biomedical Imaging and Image-guided Therapy (Division of Neuroradiology and Musculoskeletal Radiology), Medical University of Vienna, Austria

Univ.-Prof. Dr. Matthias Preusser, Head - Division of Oncology

Department of Medicine I, Medical University of Vienna, Austria

In the area of personalized therapeutic planning, stratification of glioblastoma patients based on various prognostic factors is essential either for routine patient management decision-making or clinical trial participation. Whereas most of these parameters such as histopathological and molecular characteristics, age, tumor size and localization are objectively assessable, the physical condition of the patient is based mainly on the subjective evaluation of the attending physician. Thus, the use of objective parameters to measure physical performance, such as skeletal muscle mass estimation, has recently become more common.

Methods estimating skeletal muscle mass

The reduction of skeletal muscle mass and function is defined as “sarcopenia” and was firstly described by Baumgartner et al. assigned to aging. Moreover, secondary-induced sarcopenia in various disease entities, such as chronic inflammatory diseases or cancer, has been recognized in the last few years to be an objective parameter indicating a poor prognosis due to patient frailty.

Methods such as dual X-ray absorptiometry, bioelectrical impedance analysis, or the area of lumbar skeletal muscles surveyed by computed tomography or magnetic resonance imaging (MRI) studies of the abdomen are established to estimate the skeletal muscle mass. However, in glioblastoma



Dr Julia Furtner

patients, radiological examinations of the abdomen are generally not routinely available.

In recently published studies the thickness of the temporal muscle, a muscle used for biting on each side of the head, has been shown to have a high association with the area of lumbar skeletal muscles, representing an estimation of the skeletal muscle mass, as well as with the grip strength of a person's dominant hand, indicating a measure of the muscle function and the nutrition status of patients. Thus, the temporal muscle thickness has been proposed to be a potential marker by which to identify patients at risk for sarcopenia. This is particularly advantageous for patients with neurological or neuro-oncological diseases, as the thickness of the temporalis muscle can be directly



Dr Matthias Preusser

determined on the basis of routine MRI examinations of the brain without prolonging the scanning duration and it helps to avoid additional examinations or a possible increase of the radiation dose for patients, leading to reduced health care costs.

Temporal muscle thickness as a prognostic marker

The temporal muscle has previously been proven to have the ability to predict outcome in various disease entities. In trauma patients or children with nonsyndromic craniosynostosis (the premature closure or fusion of the open areas between the skull plates in an infant's skull, the cause of which is unknown) it was associated with hospital-based clinical outcome markers, such as ventilator days or the

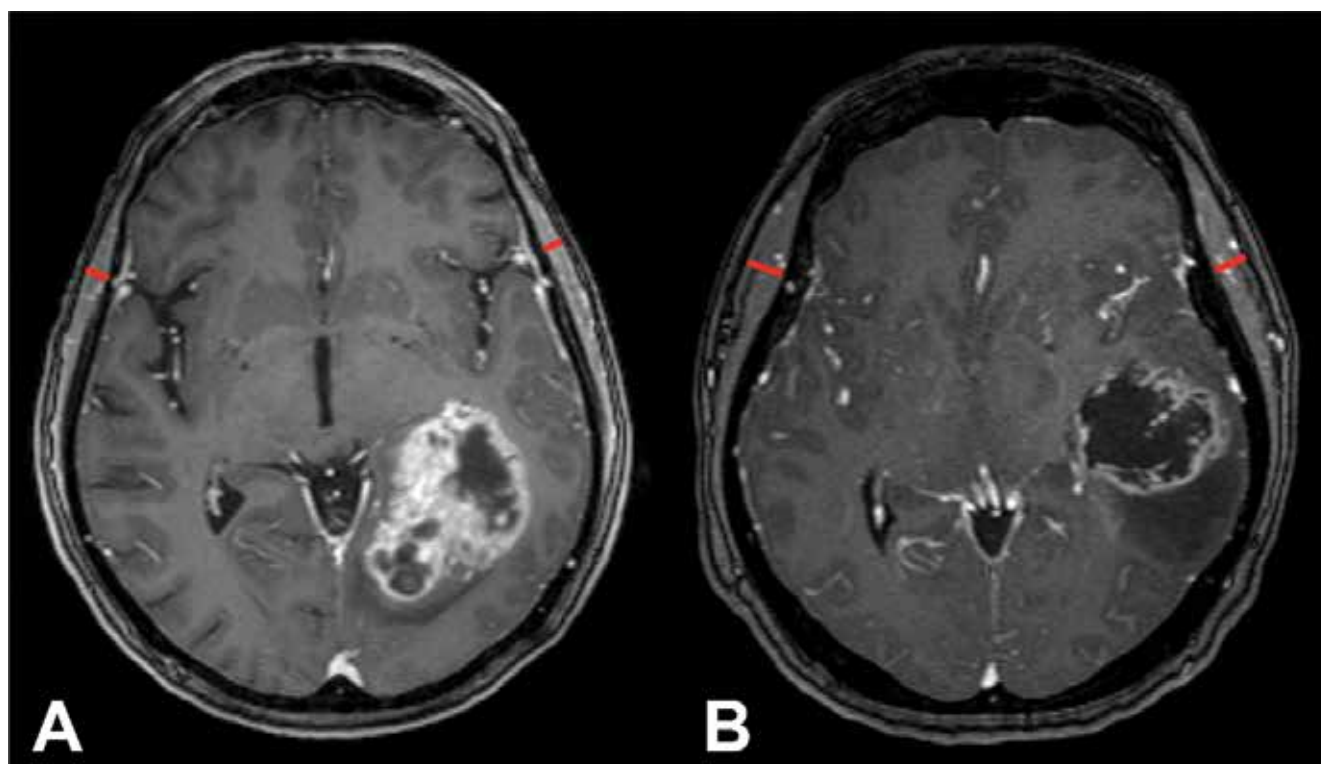


Figure 1A shows a 62-year-old glioblastoma patient at risk for sarcopenia at the time of diagnosis (temporal muscle thickness value below the sex-specific cut-off) with a significantly lower overall survival in comparison to a 63-year-old glioblastoma patient with a normal muscle status presented in Figure 1B.

lengths of the hospital stay. Recently, the thickness of the temporal muscle has been established as an independent outcome prognostication parameter in the field of neuro-oncology by identifying patients at risk for sarcopenia. In this area it showed promising results when associated with the survival of patients with brain metastases of various primary tumor types and primary CNS lymphoma. Moreover, it has also been demonstrated that the temporalis muscle thickness is an independent prognostic marker in patients with newly diagnosed glioblastoma, independent of the MGMT-promoter methylation status in large multicenter international trials (see Figure 1).

Furthermore, among glioblastoma patients already at risk for sarcopenia at the time of diagnosis, the extent of temporal muscle wasting after chemoradiotherapy was linked inversely with overall survival, but not in patients with normal skeletal muscle status. Interestingly, the temporal muscle thickness showed no correlation with the body-mass-index and only a weak association with age in these patient cohorts. This may be based on the fact

that the body mass index focuses on the patient's weight instead of the body composition and is therefore not able to identify a reduced muscle mass in an obese patient. In terms of the weak association between a patient's age and the survival prediction, the physical condition of the glioblastoma patients revealed more information than the patient's chronological age. Similar results have also been shown in large multicenter international trials in recurrent glioblastoma patients.

Impact of implementing the temporal muscle thickness in the clinical workflow

When implementing the temporal muscle thickness in routine clinical workflow, it could be used to provide an initial overview of skeletal muscle mass and function. If a patient shows a temporal muscle thickness below the sex-specific cut-off value further testing will be required to confirm the diagnosis of sarcopenia. These measurements should be taken into account at the diagnosis as well as on a regular basis in the follow-up MRI examinations

to monitor the muscle status in a longitudinal manner.

If detecting patients with newly developing sarcopenia or patients whose conditions worsen under the course of their disease, the implementation of appropriate strategies for skeletal muscle mass and function preservation, such as nutritional support and resistance training may improve patients' outcomes by reducing skeletal muscle wasting. ■

To read more about this topic, please see the paper "Temporal Muscle Thickness as a Prognostic Marker in Patients with Newly Diagnosed Glioblastoma: Translational Imaging Analysis of the CENTRIC EORTC 26071-22072 and CORE Trials" published in *Clinical Cancer Research*, the journal of the American Association for Cancer Research - *Clin Cancer Res* (2022) 28 (1): 129-136, <https://doi.org/10.1158/1078-0432.CCR-21-1987>



DIPG/DMG SYMPOSIUM WORKSHOP

The Warrior Lantern Lighting ceremony at the 2021 International
DIPG/DMG Symposium held in Houston, Texas, USA

Host to International Innovation

The DIPG/DMG International Symposium Enters its 10th Year
with November 2021 Meeting in Houston Texas

Keith Desserich, Chairman and Co-Founder
The Cure Starts Now



In 2010 it started as a challenge. Twenty of the world's preeminent experts on neuro-oncology were gathered in one room to consider the potential of a "homerun cure". Initially it was intended to be a one-day meeting with wide sweeping discussions to assess consensus, nothing more. What it became was a two-day conference with over 100 experts, setting the future of what would become one of cancer research's foremost conferences. And the cancer it would seek to cure was one of the most elusive pediatric brain cancers – diffuse intrinsic pontine glioma (DIPG)/diffuse midline glioma (DMG). That meeting started the journey that many believe will refine how we approach a total cure strategy for this devastating disease.

The International DIPG/DMG Symposium – some history

That meeting was the first International DIPG/DMG Symposium presented by The Cure Starts Now Foundation. Held ten years ago, it became the foundation of many of the advancements we see today in diffuse intrinsic pontine glioma, diffuse midline glioma and even with

other pediatric cancers. The partnerships achieved through this forum have led to the development of new drugs, new ways of administering radiation, new surgical procedures, new international studies and most of all, a revolutionary way of sharing and analyzing data. At its core, it assembled a unique collaboration of both researchers and parents, unified to work as one in ways that previously had not been attempted. A biennial event, it not only aligns the goals of the DIPG/DMG community but also seeks to establish collaborations for future successes.

More than just a review of research, The DIPG/DMG Symposium was historically designed to be an interactive workshop between leading medical experts and family-led foundations. Realizing that the best research comes from a multi-disciplinary approach, implementation teams are formed from basic, translational and clinical concentrations – all in the presence and with the support of families and foundations to assist with insight and pre-secured funding channels. Big ideas are allowed to grow bigger, not smaller and more restrictive. Here

research can be promoted in generational ways that lead to "next step" planning even before the conclusions are published. The result is efficient research in less time and constant "dream team" concepts that lead to unprecedented innovation.



Dr. Mariko DeWire-Schottmiller (center) receives the Lauren Hill Full Court Press Award from Lisa Hill (far left) of Lauren's Fight for Cure and Brooke Desserich (far right) of The Cure Starts Now ➤



The 2021 International DIPG/DMG Symposium was attended by 66 independent foundations and chapters, over 50 leading researchers in the field, five industry partners and 49 DIPG/DMG families

The November 2021 DIPG/DMG Symposium

The November 2021 DIPG/DMG Symposium was held at the Woodland's Conference Center in Houston, Texas, USA. Sponsors included The Cure Starts Now, Snapgrant.com, The Brooke Healey Foundation, PTC Therapeutics, Aminex Therapeutics, and Midatech Pharma.

The 2021 Symposium was co-hosted by chapters of The Cure Starts Now Foundation and the DIPG/DMG Collaborative partners:

- The Brooke Healey Foundation
- Aidan's Avengers
- Aubreigh's Army
- Cure Brain Cancer
- The JTHF Foundation
- Laurie's Love
- Melina Michelle Edenfield Foundation
- The Musella Foundation
- Pray Hope Believe Foundation
- Reflections of Grace
- Run DIPG
- Storm the Heavens
- The Gold Hope Project
- Love, Chloe Foundation
- Isabella and Marcus Foundation

- Lauren's Fight for Cure
- Robert Connor Dawes Foundation
- Lily LaRue Foundation
- Marlee's Mission
- Ryan's Hope
- The American Childhood Cancer Organization

The four-day session featured workshops on the developments of the International DIPG/DMG Registry, The SIOPe DIPG Registry, partner/chapter workshops and a two-day ambitious discovery of new trends and key research. Researchers provided a periodic update on the results of nearly US \$18 million in research at 115 hospitals, 15 countries worldwide and a combination of 108 research projects. This innovative symposium once again achieved "sold-out" status despite adherence to social distancing standards because of the COVID-19 pandemic. Overall, the meeting represented an unparalleled effort of 66 independent foundations and chapters, over 50 leading researchers in the field, five industry partners and 49 DIPG/DMG families.

Highlights of the conference included a networking dinner where Dr. Stewart Goldman of Phoenix Children's Hospital

was awarded the "DIPG/DMG Collaborative Researcher of the Year" and Dr. Mariko Dewire-Schottmiller was awarded the "Full Court Press Award." Additionally, in an unorthodox four-minute grant challenge featuring finalists competing for the \$50,000 Cure Fund Grant, Dr. Bakhos Tannous of Massachusetts General Hospital won for his project titled "Targeted Protein Degradation for DIPG Therapy".

A special combinatorial therapy and options workshop was moderated by Dr. Adam Green of Colorado Children's Hospital in association with Dr. Matthew Dun (University of Newcastle, Australia), Dr. Jamie Anastas (Baylor College of Medicine, USA), Dr. Stergios Zacharoulis (Columbia University, USA), Dr. Carl Koschmann (University of Michigan, USA), Dr. Nick Vitanza (Seattle Children's Hospital, USA) and Dr. Arzu Onar (St. Jude Children's Research Hospital, USA). This was followed by a much-anticipated workshop on research and industry partnerships led by Dr. Roger Packer of Children's National Hospital in the United States.

Through a parallel workshop structure, families were able to participate in discussions regarding survivorship,



Dr. Stewart Goldman (center) receives the “Collaborator of the Year” award from the DIPG/DMG Collaborative – with Steve Healey (far left) of the Brooke Healey Foundation and Keith Desserich (far right) of The Cure Starts Now Foundation

As in the past, the first formal day of presentations at the 2021 International DIPG/DMG Symposium featured breaking updates from Dana Farber, Children’s National Hospital, Cincinnati Children’s Hospital, Children’s Cancer Institute of Australia, University of Newcastle, Phoenix Children’s Hospital, Seattle Children’s Hospital, Northwestern University, St. Jude Children’s Research Hospital, Columbia University, Sydney Children’s Hospital, Massachusetts General Hospital, Lurie Children’s Hospital of Chicago, Nationwide Children’s Hospital, Baylor College of

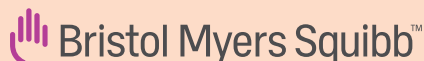
Medicine, UPMC Children’s Hospital, Duke University, The Institute of Cancer Research, Children’s Hospital of Colorado, The Hospital for Sick Children, Bambino Gesù Children’s Hospital, University of Queensland Diamantina Institute, Princess Maxima Center, Telethon Kid’s Institute, Michigan University, PBTC Consortium, PNOG Consortium, CONNECT Consortium, and the SIOPE Consortium. Day two sessions included discussions on future initiatives and collaborative approaches.

a “Progression and Re-Irradiation” discussion led by Dr. Lindsey Hoffman (Phoenix Children’s Hospital, USA, and the International DIPG/DMG Registry) and Dr. Trent Hummel (Cincinnati Children’s Hospital, USA and the International DIPG/DMG Registry). There was also an opening networking session offered by

Brooke Desserich (The Cure Starts Now Foundation) and Steve Healey (Brooke Healey Foundation).

Other family highlights also included a Warrior Lantern lighting, an unprecedented Survivor Forum Discussion and a Texas-themed Gala raising over \$75,000 for DIPG/DMG research. ■

The 7th International DIPG/DMG Symposium is scheduled for May 18-20, 2023 in Lexington, Kentucky USA. To participate, sponsor or learn more about the upcoming events, please visit www.dipg.org or contact info@thecurestartsnow.org.



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The ride to solidarity for neuro-oncology children and their families

Federica Fiorletta
Fondazione HEAL

"You treat a disease, you win, you lose.

You treat a person, I guarantee you, you'll win, no matter what the outcome." - Patch Adams

Fondazione Heal is a non-profit organisation in Rome, Italy founded by families of children affected by brain tumours. The Fondazione was born from the commitment of this group of families sharing a profound experience of pain, which has been turned into a direct and immediate action to support projects in the paediatric neuro-oncology research field.

First as individuals and then as a group, we are committed to providing financial support to scientific research projects in order to favour the study and the cure for paediatric central nervous system tumours which, although rare, are the most common solid tumours in the paediatric age, representing a leading cause of death or permanent side effects and deficits among children.

However, we have set our goal to helping research a cure for both the body and the soul - both biologically and existentially speaking. Indeed, we firmly believe that a treatment for the body would not be possible if the person - in this case, the child - is not considered as an indissoluble whole of body and soul during the whole healing process.

Why "Solidarity Taxis"?

This is also the creed behind our project of the "Solidarity Taxis". This is a completely free-of-charge transportation service, which has been available in Rome since 2021. Our "Solidarity Taxis" have been created for those families and their children who need to reach centres specialised in the care of



With its bright colours, this Solidarity Taxi is a colourful support for young brain tumour patients receiving care and support at the Bambino Gesù Children's Research Hospital in Rome, Ita

paediatric cancers and can have a hard time moving around a big city like Rome.

It may appear that this project deviates from our higher purpose of supporting scientific research in paediatric neuro-oncology. Instead, we believe that our Solidarity Taxis serve an important purpose in our work as well, because of our broader mission to offer all-round support to children with brain tumours and their families.

When a child falls ill with cancer, the whole family falls ill too. Families also have to deal with practical problems or

difficulties. And sometimes those problems and difficulties are not secondary at all.

In Italy, for instance, there are very few centres of reference on rare diseases. Among them is the Bambino Gesù Children's Research Hospital, a centre of excellence in healthcare institutions. The Bambino Gesù is based in Rome and has branches across the whole city. People go there from across the nation but also from abroad. They come from afar and sometimes parents are also forced to leave their job to follow and take care of their children. ➤

Helping to heal the children and their families

Thus, Fondazione Heal - which is a partner of the hospital - has thought of the "Solidarity Taxis", so as to make the neuro-oncology disease and the healing process of children easier to manage for some families.

From 2021 to date, we already have five "Solidarity Taxis" in Rome, giving an average of three rides per day. We estimate to have already transported little brain tumour patients and their families more than 240,000 km during their treatment journey at the Bambino Gesù Children's Research Hospital!

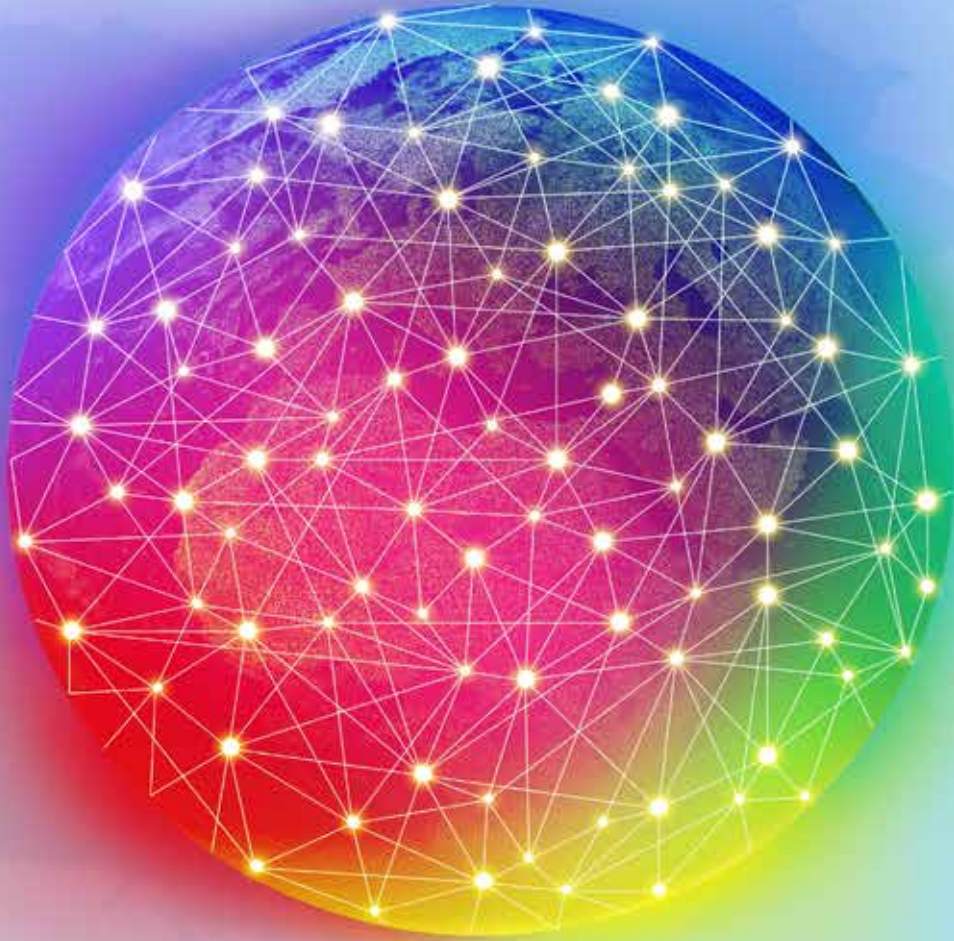
We say to all: "Join our ride to solidarity with kindness and courage". ■

For more information about Fondazione Heal's "Solidarity Taxis" and the additional activities of the organisation, please visit: <https://www.progettoheal.com/>



Another Fondazione Heal Solidarity Taxi hits the road in Italy!





BRILLIANCE!

A virtual exhibition of creative works from
the global brain tumour community *

November 2021

*This part of *Brain Tumour* magazine reproduces the 2021 online Brilliance! catalogue which can also be found at https://issuu.com/ibta-org/docs/ibta_brilliance_catalogue . For optimal viewing of the artworks in Brilliance!, and to see the colours more vibrantly, we suggest you look at them online.

*"The brilliance of art
as a collectible is that
it has a way of reaching out
on an emotional level.
It touches on mystery,
even spirituality."*

Robert Genn (May 15, 1936 – May 27, 2014), Canadian painter



Welcome to the first “Brilliance!” virtual exhibition.

November 2021

Pablo Picasso is reputed to have said that “the purpose of art is washing the dust of daily life off our souls”. So with that thought in mind, the International Brain Tumour Alliance (IBTA) is very excited to welcome you to “Brilliance!”, our inaugural virtual art exhibition.

People affected by a brain tumour make up a diverse population of patients, family members and friends, men and women, young and not so young, from every culture and walk of life. The same can be said of the healthcare professionals who provide care and do research in the brain tumour community.

While modern medical care strives daily to treat the whole person, it is also true that receiving brain tumour treatment can be very challenging for patients and their families. It is also complex and demanding for the many healthcare professionals who prescribe and provide that treatment and care.

Frequently, the urgency and complexity of discussing medical treatments and other issues surrounding brain tumour care, means there just isn't time to talk of other things such as, for example, an individual's interests, passions and talents.

It is from that practical reality, that the idea of “Brilliance!” arose as a way to shine a bright, uplifting light on the talents of those in the international brain tumour community and to share a little bit more of who we are, beyond the impact of a brain tumour in our lives.

We warmly invite you to take some time to enjoy a virtual stroll through the remarkable works of “Brilliance!”. We urge you to read the words of the artists as they explain why they chose to express themselves in a particular way and how a brain tumour has affected them*. The works of art in the “Brilliance!” exhibition are as diverse and inspiring as the people who have created them.

The Brilliance Exhibition Committee and Exhibition Curators:

Kathy Oliver Chair/Co-Director, International Brain Tumour Alliance (IBTA)

Maureen Daniels BScN, RN, IBTA Senior Advisor

Rosemary Cashman MA, MSc(A), NP(A), IBTA Senior Advisor

The “Brilliance!” virtual catalogue was designed by Edwina Kelly of Edwina Kelly Design (edwina@edwinakellydesign.co.uk)
Copyright of the individual artworks included in the “Brilliance!” catalogue remains with the individual artists who submitted them (save where otherwise specifically stated and acknowledged). None of the images contained in the “Brilliance!” catalogue may be reproduced in any other form whatsoever without the express permission of the artist (or, where the copyright is acknowledged to belong to a third party, the express permission of the third party shall be required). Please contact kathy@theibta.org for further information.

*The text for some of the entries reproduced in *Brain Tumour* magazine may have been shortened from the original version of the text online at https://issuu.com/ibta-org/docs/ibta_brilliance_catalogue



Ellen Victoria Sawkins

Australia

Title of creative work: The Deep

Medium: acrylic and spray paint

This piece was created in the only space where my fatigue recedes and my spirit energises. I get lost in the inspiration of my coastal environment. I am immersed and at peace.

My brain tumour is inoperable and does create some challenges. I have had to learn not to panic with new symptoms. I am a witness to my brain's independence. Life is bittersweet now, but I am lit up by small wins and am so grateful for what I can still achieve. It is not easy and it is a conscious effort, but I am loved and I'm proud of who I know myself to be when in the dark.



Sandra E Ball

United Kingdom

Title of creative work: "Long Days – a portrait of Dr Walayat Hussain"

Medium: Watercolour

I underwent surgery to remove a rare form of brain tumour, vestibular schwannoma, in May 2011. I always say I am a walking miracle as it was well stuck to the facial nerve, as well as the hearing and balance nerves. I was blessed to have the best possible neurosurgeon and medical team for the surgery. I love to draw and paint as it not only helps the cognitive skills, it takes me out of myself, makes me concentrate and gives me joy. This watercolour painting was given to Dr Hussain as a thank you, September 2020, as I underwent the last surgery on my nose, after suffering from a rare form of skin cancer two years ago. I had made a pencil sketch of Dr Hussain which I presented to him the day after surgery. He is such a busy man who works with a spirit of excellence, often going the extra mile, so the title 'Long Days' is very apt. I was drawn to his wonderful colourful head covering, and of course, his eyes which show compassion and care.



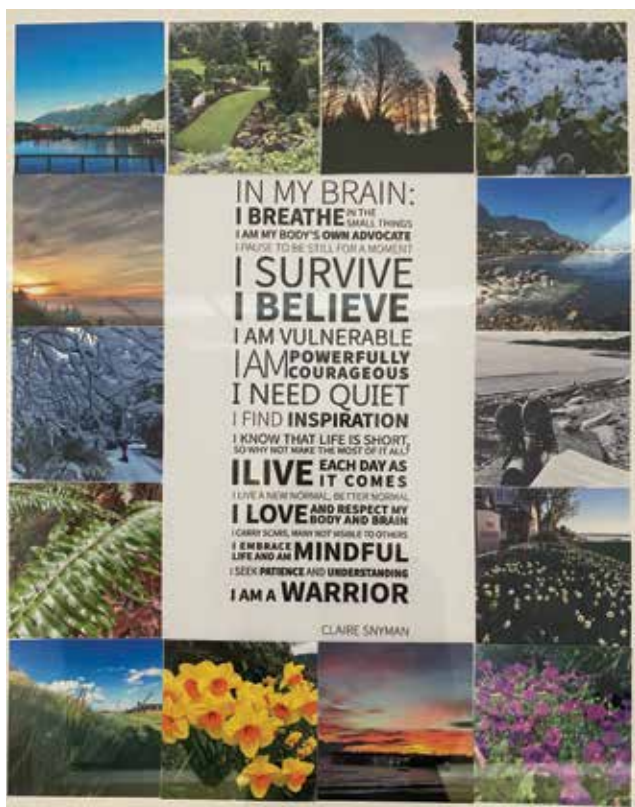
Stephen Ménage

United Kingdom

Title of creative work: "Study of fellow artist's head"
Medium: ciment fondu

Stephen's mother explained that Stephen suffered from a recurring brain tumour, beating it time and time again, until April 2021 when sadly he died in hospital whilst recovering from the latest operation. He never complained and found music and the arts a great comfort when things got bad.

Stephen belonged to a local sculpture group and this ciment fondu head is one of his works of a fellow artist. It resides in our garden - hence the rather weather beaten look.



Claire Snyman

Canada

Title of creative work: "In My Brain"
Medium: photographs

When I was having to contemplate a potential second brain surgery, I felt very depressed. I came across the 365 Gratitudeproject and took photos each day of things I was grateful for. Some of these photos frame a mantra of words that epitomise my brain tumor journey.

Both myself and my family have been affected by my brain tumour. On the positive side, I feel more grateful for so much and see life through a different lens. My short term and long term memory loss plus cognitive challenges have required many regular adaptations, including for my career. While this requires extra work each and every day, I have been lucky enough to find rewarding and purposeful work, meet inspiring people and go down paths I would never have done before. This doesn't mean I haven't grieved my loss. It means I have found some doors that have opened, where others may have closed.



Tricia Ann Roloff

United States

Title of creative work: "Tahiti Days"

Medium: photographic image

"My first travels after years of being a caregiver myself."



Giuseppe Raschiani

Italy

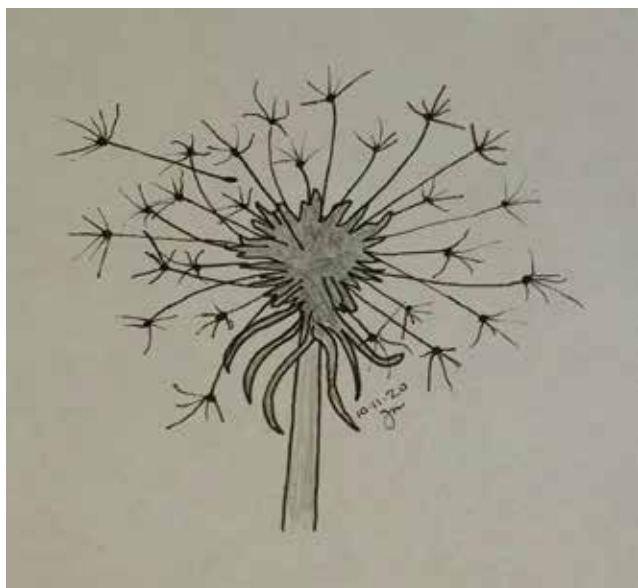
Title of creative work: "Emotions"

Medium: acrylic on canvas

I had an attack of epilepsy at Christmas 2020. Suddenly, in the hospital after an MRI I was told that I had a brain tumour that was likely glioblastoma at stage IV. I had brain surgery in less than five days later then I began a standard treatment plan with radiation and chemotherapy. Today, I feel good overall. I have so many moments where I get to enjoy life with my family, my son and my friends.

These paintings are an expression of my energy that manifests itself in colours and shapes. The title says the meaning. This energy radiation can be seen as a big explosion of emotions. Each of us can live it according to his perception and sensitivity. For me these are space colours of vital and sexual energy.





Jami Millon

United States

Title of creative work: "Breathe"

Medium: coloured pencil and pigmented ink

"I was diagnosed with oligodendroglioma in March of 2018. I am currently undergoing treatment. 'Breathe' reminds us how fragile the world is and how powerful we are...even with a single breath."



Rosemary Cashman

Canada

Title of creative work: "Lila"

Medium: Pan pastel and charcoal

As a nurse practitioner in neurooncology for almost 25 years, I have had the good fortune to know so many brave, generous, talented, funny and wise people, often in authentic and inspiring ways. These relationships have profoundly affected my life.

I love animal faces of all sorts, including human ones. Here is one I have come to know.



Scott Norris

United States

Title of creative work: "Urban Flower"

Medium: digital photograph

"Urban Flower is a digital photographic depiction of a flower thriving in a harsh, urban, concrete-filled environment."



Stephen Ménage

United Kingdom

Title of creative work: "Love Spoon"

Medium: Wood

Stephen's mother explained that Stephen suffered from a recurring brain tumour, beating it time and time again, until April 2021 when sadly he died in hospital whilst recovering from the latest operation. He never complained and found music and the arts a great comfort when things got bad.

Stephen carved this spoon for his fiancée, Janie, as a token of his love and to celebrate their relationship.



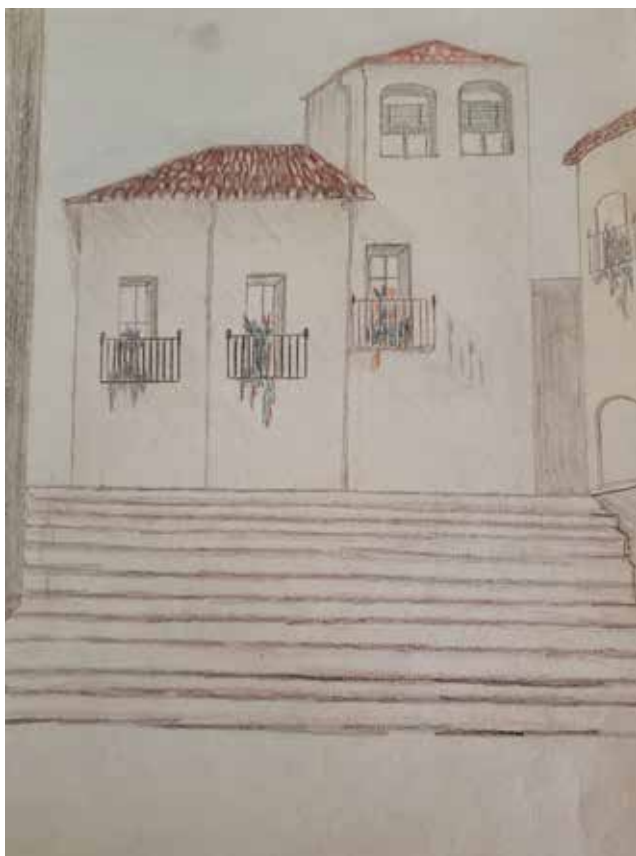
Jenny Hyslop

United Kingdom

Title of creative work: "Bude, Cornwall – Barrel Rock"

Medium: acrylic on canvas

I was diagnosed with anaplastic astrocytoma, grade 3, in May [2021]...This came about out of the blue after worsening migraines and becoming more unstable on my legs and suffering falls... I have been able to enjoy my art while being home unable to work. It allows me to forget about the treatment and situation and my life-changing challenges...This is an acrylic painting of Bude, north Cornwall in the United Kingdom. I have always enjoyed painting and this is an area near to where I live. I find painting absorbs my concentration and prevents me worrying about my brain tumour. I love to paint for people and for raising money for charity such as the sea pool at Bude, Cornwall, and for the brain tumour support group.



Tricia Ann Roloff

United States

Title of creative work: "Bohemian Life"

Medium: coloured pencils on paper

I had a lot of emotional ups and downs because my tumor affected my hormones. Things got better after my surgery. The one consistent thing in my life has been my photography. Photography is fun, creative and helps see life in a different way wherever you find yourself. I love architectural and seascape photography in particular. The architecture of Europe blew my mind. I encourage everyone to pursue an artistic endeavour.

After college (fine arts degree) I travelled around Europe. In Madrid my camera was stolen, so I bought colored pencils and commenced to live my Bohemian Life, sitting in the streets and drawing. It was a very calming experience in the midst of some unusual symptoms I was having at the time (later to be the pituitary tumor diagnosis). I continued to draw throughout my travels.



Rosemary Cashman

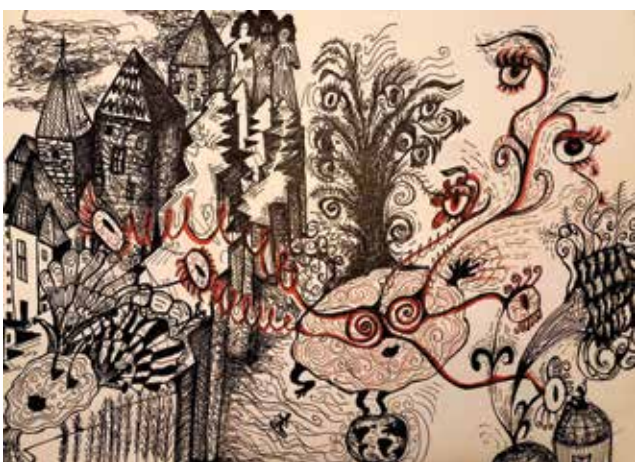
Canada

Title of creative work: "Jack"

Medium: Pan pastel and charcoal

As a nurse practitioner in neurooncology for almost 25 years, I have had the good fortune to know so many brave, generous, talented, funny and wise people, often in authentic and inspiring ways. These relationships have profoundly affected my life.

I love animal faces of all sorts, including human ones. Here is one I have come to know.



Anonymous

Croatia

Title of creative work: "The Hint"

Medium: pen on paper

I have been a patient since 2015. Thanks to modern medicine and my family I am healthy today and have another chance of life. There are other patients who need a chance for life.

This painting was created two years ago just before my brain tumour. I call this painting "The Hint" because this was my first and only sign that something was wrong. Today I am healthy and hope this picture will be only the memory about what has happened in my past.



Rebekah Bagguley

United Kingdom

Title of creative work: "Love"

Medium: acrylics

I have been living with a brain tumour diagnosis and the effects of surgery and treatment since 2005 when I was 27. It progressed from Grade 2 Astrocytoma to Grade 3AA (anaplastic astrocytoma) in 2011. I still grieve for the life I thought I would have (children, well paid career, a partner, not to mention the weight gain due to steroids) But I have had to adapt to the many challenges and am managing to live a better life by learning new skills. Painting has become a real pleasure and helps me through times when I feel fatigued, anxious, and hopeless.

This is one of my first paintings of my best friend Archie. He could be credited with life-saving abilities as he has been a source of pure joy for me through the toughest of times.



Ellen Yates

United Kingdom

Title of creative work: "Gramma's Love Angel"

Medium: crochet

I was diagnosed with an acoustic neuroma brain tumour in April 2015 and have been on watch and wait since that time. I have regular MRI scans to keep an eye on it. I am now ill-health retired. Among my various symptoms, I have balance issues, tinnitus, brain fatigue/fog, memory loss, dizzy spells, anxiety/depression.

Using a very small crochet hook and fine yarns I decided to have a go at crocheting an angel. I was commissioned to make this item for a friend of mine at Christmas - a challenge I enjoyed and she was very happy with the finished result. Crochet is my 'zone out' craft.



Giuseppe Raschiani

Italy

Title of creative work: "Joy"

Medium: acrylic on canvas and vinavil

I had an attack of epilepsy at Christmas 2020. Suddenly, in the hospital after an MRI I was told that I had a brain tumour that was likely glioblastoma at stage IV. I had brain surgery in less than five days later then I began a standard treatment plan with radiation and chemotherapy. Today, I feel good overall. I have so many moments where I get to enjoy life with my family, my son and my friends.

These paintings are an expression of my energy that manifests itself in colours and shapes. The title says the meaning. This painting shows flares of bright and vivid colours, the colours of love. The love match between man and woman. What else?



Jami Millon

United States

Title of creative work: "I will survive!"

Medium: coloured pencil and pigmented ink

I have an oligodendroglioma, grade 3. I have survived since March 2018. This piece is a layout of brain tumor ribbons along with traits that I have commonly found in individuals battling brain tumors.



Matthew Mallett

Australia

Title of creative work: "Lost in the Fog"

Medium: photograph

In 2007 I was diagnosed with a low grade oligodendroglioma tumour. Since then, I have undergone chemo, further surgery to debulk the tumour, radiation, more chemo. Am still here and thankful!

This piece I captured some time ago. The easiness of the fog, trees and the duotone look make me want to get lost in this place...to explore further.



Stephen Ménage

United Kingdom

Title of creative work: "Bust of a Fellow Sculptor"

Medium: ciment fondu

His mother explained that Stephen suffered his first brain tumour (ependymoma) shortly before his 19th birthday. It recurred in 2002, then 2005, 2014 and finally in 2020. He was told it would keep recurring and he used to refer to it as his "sword of Damocles". Despite this he always led a full and active life right up to the week before his final operation enjoying long walks and cycle rides with his fiancée. His love of music and sculpture provided great comfort when things got bad. In March of this year his swallowing shut down and he had to have a tube fitted into his stomach for his food and drink to go down. Stephen's last operation, delayed from 2020 because of Covid, finally went ahead in April of this year but sadly he passed away a couple of days later.

This work is a head that Stephen sculpted of one of the people in the same sculpture group as himself.



Brian Short

United Kingdom

Title of creative work: "Cadgwith Cove, The Lizard, Cornwall"

Medium: water colour on paper

My eldest daughter has been diagnosed with a brain tumour this year (2021) in May, with a grade 3 anaplastic astrocytoma. She had two emergency operations in May and has undergone radiotherapy and now started chemotherapy. It has been a worrying time but as a family we work together and have a shared interest in art and painting.

This is an original watercolour of Cadgwith Cove on The Lizard in Cornwall, UK.



Telma Costa

Portugal

Title of creative work: "Fighting the Fears – Self Portrait"

Medium: digital photography

As a medical oncologist, I remember all of my patients with primary and secondary brain tumours. As a daughter, I honour the memory of my mother, who died with brain metastasis. And finally, as a cancer patient, I fight the fear of uncertainty and try every day to keep my mind clear and my heart wide open, so I can allow myself to have a good life.

During chemotherapy, photography appeared as a creative and honest way of communication and expression of some of my deepest feelings. It was pleasant company, and in the future it won't let me forget some of the most important things I've learned.



Sharon Carter

United Kingdom

Title of creative work: "Water's Edge"

Medium: acrylic paints on canvas

I have been a brain tumour patient for two years. I have an intracerebral plasma cell granuloma deep in my brain that is inoperable. I have had plasma exchange, rituximab therapy, seven months of chemotherapy and I just finished radiotherapy. Nothing to date has improved the tumour. In this time, I have had to retire from my 32-year career as a nurse due to the problems it has left me with. I have a great family and continue to remain positive for the future and hope to stay as I am if not to improve. I suffer with headaches, spatial awareness problems and memory problems. Painting is something I do to relax.

"Water's Edge" is my interpretation of a calming riverbank, it being allowed to grow as it wishes.



Jan Watson

United Kingdom

Title of creative work: "Only a Fool"

Medium: sand carved glass

Before my craniotomy my neurosurgeon informed me to be prepared that I may not be able to return to working as a stained glass artist with my wife, Dawn, in the business we started together. Little steps at a time and a lot of support from Dawn and we are functioning as a team again although a little slower than before. Yes, the world of stained glass can be hectic at times.

Only a fool, tempting though it possibly is, upon the vague chance of coming across an angel's trumpet, one is best advised to leave well alone and don't tempt fate!



Jami Millon

United States

Title of creative work: "Resting Cardinal"
Medium: coloured pencil and pigmented ink

I was diagnosed with grade 3 oligodendroglioma in 2018 and am currently undergoing immune checkpoint inhibitor treatment. Cardinals symbolize courage and all cancer patients have remarkable courage.



Sharon Carter

United Kingdom

Title of creative work: "Beach Before the Storm"
Medium: acrylic paints on canvas

I have been a brain tumour patient for two years. I have an intracerebral plasma cell granuloma deep in my brain that is inoperable. I have had plasma exchange, rituximab therapy, seven months of chemotherapy and I just finished radiotherapy. Nothing to date has improved the tumour. In this time I have had to retire from my 32 year career as a nurse due to the problems it has left me with. I have a great family and continue to remain positive for the future and hope to stay as I am if not to improve. I suffer with headaches, spatial awareness problems and memory problems. Painting is something I do to relax.

In "Beach Before the Storm", this is a different feel to a tropical beach before a storm comes in.



Sandra E Ball

United Kingdom

Title of creative work: "A Favourite at the Zoo"

Medium: Watercolour

I underwent surgery to remove a rare form of brain tumour, vestibular schwannoma, in May 2011. I always say I am a walking miracle as it was well stuck to the facial nerve, as well as the hearing and balance nerves....Being a member of my local zoo I love to go to watch the animals/wildlife progress. It is always a source of inspiration and a good exercise regime as it covers acres. The Magellanic Penguin (the smallest of the penguin species) fascinates me. I have watched the chicks grow up into adults and when the zoo is quiet they always come near to see who is looking. This painting is one of several I have done of the penguins. It is an exercise in tones and also textures. The rocks are more colourful in my painting than in real life and I think make for an interesting background.



Joseph Lee

Singapore

Title of creative work: "Origami Mystic Dragons"

Medium: foil paper

This piece of origami is very elegant and it's a special design with wings that can extend and contract at will. It means a lot to me as it showcases my determination to finish my own workpieces and not giving up on anything or any time.

I have double vision and I don't really know how I'm able to just use my left eye to focus through my daily life and make origamis.



Jenny Hyslop

United Kingdom

Title of creative work: "Port Isaac, North Cornwall"

Medium: acrylic on canvas

I was diagnosed with anaplastic astrocytoma, grade 3, in May [2021]...This came about out of the blue after worsening migraines and becoming more unstable on my legs and suffering falls... I have been able to enjoy my art while being home unable to work. It allows me to forget about the treatment and situation and my life-changing challenges...This is an acrylic painting of Port Isaac, north Cornwall in the United Kingdom. I find painting absorbs my concentration and prevents me worrying about my brain tumour. I love to paint for people and for raising money for charity and for the brain tumour support group.



Maureen Daniels

Canada

Title of creative work: "Frosted Fox"

Medium: digital photograph

For over 30 years I have had the privilege and honor to work in the neuro-oncology community, in my own institution, within Canada and internationally. I am inspired daily by the courage and strength of my patients and their families and by the dedication and energy of the neuro-oncology community around the world.

My weekdays are spent in a busy, demanding environment, and on the weekends, my partner and I are fortunate to escape to our Fox Lake retreat in beautiful Muskoka, Ontario, Canada. We woke one morning to this magical, frosty scene in early November. I took this photograph with my phone and no filters added. Mother Nature doesn't need any help to create beauty!



Matthew Mallett

Australia

Title of creative work: "In Search of Affection"

Medium: photograph

in 2007 I was diagnosed with a low grade oligodendroglioma tumour. Since then, I have undergone chemo, further surgery to debulk the tumour, radiation, more chemo. Am still here and thankful!

This image was captured at the Werribee Open Range Zoo (Australia) of a new born cub looking for affection from his father. The pleasure on the cub's face makes one feel totally at ease and trusting of the surroundings.



Wow Warli by Megha

India

Title of creative work: "Yin Yang Pattern in Warli Art Form"

Medium: hand painted on a wall with acrylic colour

I depicted this yin yang through my Warli painting, which shows the balance in life. This personally motivates me and generates a lot of positivity always. Warli is a tribal art form, which is originally from Maharashtra in India. Warlis are the oldest tribes of India.



Nick Dawes

Australia

Title of creative work: "Brain I"

Medium: oil on canvas

'Brains' was a series completed in 2014 as a part of my year 12 VCE Art portfolio submission. The series focused on my older brother Connor who passed away in 2013 from an ependymoma brain tumour. The works in the series explore his battle with brain cancer, depicting his struggles and anguish in a bright contradictory tone reflecting his personality throughout his journey.

'Brain I' depicts Connor's vibrant and colourful brain being pulled apart by his brain cancer. The work shows the brain in transition where it is unknown whether it could slide back together or be pulled further apart.



Jaya Pal

India

Title of creative work: "Girl with Little Friend"

Medium: paint and pen on paper

This drawing shows the friendship of a little girl with her pet and how an animal and a human being can be connected with each other.

I am 18 years old and was diagnosed with a brain tumour in 2020 with symptoms of headache and seizures.



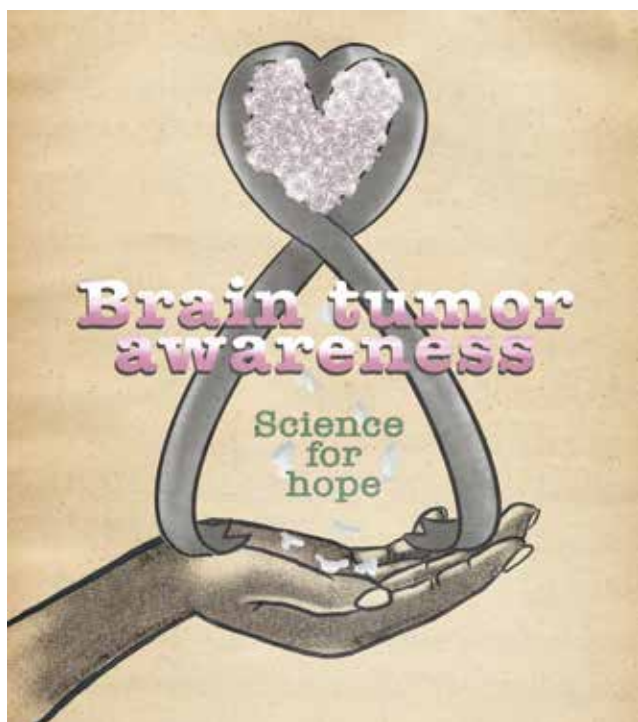
Ben Winters

New Zealand

Title of creative work: "Miracle Baby Over the Moon"

Medium: photograph

My life was flipped upside down when I was diagnosed with GBM in May 2017. Brain cancer has definitely taught me to value life and to make the most of those special moments with family and friends. This image of my amazing seven-month pregnant wife, five year old boy and unborn child was photographed by me at a public moon exhibition in my hometown of Upper Hutt, New Zealand. This was a brilliant opportunity that could not be missed. When I was diagnosed with GBM in May 2017, I was told I would be lucky to live two years, and we would never have any more kids due to the chemo and radiation treatment. After having my fertility tested in 2019, it was confirmed there was next to no chance of having any more babies. This was something we as a family struggled with and I carried guilt for as we had planned more. But on 23rd July 2021 I held in my arms my healthy miracle baby. Guess you could say we were over the moon.



Junko Shimazu

Japan

Title of creative work: "You Are Not Alone"

Medium: digital illustration

My sister was diagnosed with oligodendroglioma in 2020. My sister is my best friend, and I was devastated when I learned about her situation. Because of its rarity, the journey to battle this disease often feels lonely for patients and family members. I created this artwork to remind myself that we are not alone, and collective efforts, understanding, and knowledge from each person will lead us to more awareness of this terrible disease. Most importantly, I strongly believe that scientists can help gather everyone's experiences and to help provide a brighter future for patients and their family members.



Lynda Tse

New Zealand

Title of creative work: "Wanda the Friendly Witch"

Medium: wooden clothes peg, fabric, beads, mohair, button and other decorative materials

In 2006 I was diagnosed with a glioblastoma (GBM). Designing and crafting these small peg dolls played a huge part in my healing process. I was able to focus on creating these little characters which I collectively called "Peglets"...I have found making peg dolls a way of escaping the harsh reality of having a brain tumour. However, I am lucky to be here and in good health, other than a few issues with my balance which the neurologist has put down to long term radiation effects...Peglets are wooden peg dolls which I design and hand-craft in Wellington, New Zealand.



Abhilasha Azad

India

Title of creative work: "Money Box from Protein Powder Box"

Medium: painted plastic

My husband has been affected by a brain tumour, grade 3 oligodendroglioma and has been diagnosed and treated one year back. He has completed his chemotherapy and radiotherapy in September.

I have made a money bank from a protein powder box. Best use of waste box, which we threw in the garbage. And it has beautiful painting of ancient Mughal Dynasty.



Jenny Hyslop

United Kingdom

Title of creative work: "St Ives, Cornwall"

Medium: acrylic on canvas

I was diagnosed with anaplastic astrocytoma, grade 3, in May [2021]...This came about out of the blue after worsening migraines and becoming more unstable on my legs and suffering falls... I have been able to enjoy my art while being home unable to work. It allows me to forget about the treatment and situation and my life-changing challenges...This is an acrylic painting of St Ives, Cornwall in the United Kingdom. I find painting absorbs my concentration and prevents me worrying about my brain tumour. I love to paint for people and for raising money for charity and for the brain tumour support group.



Dawn Watson

United Kingdom

Title of creative work: "Autumn Leaves"

Medium: stained glass

My husband was diagnosed with an astrocytoma with IDH mutation in August 2019. This came completely out of the blue to us, sending us on a rollercoaster of emotions and uncertainty... To add to the worries of the future, we also work together running our own stained glass studio which we have done for the past 38 years. When my husband was told he might not be able to do the work he loves after his surgery, it was shattering. Thankfully, two years on (2021) he can, regaining his skills so our creations together continue ... perhaps at a slower pace. I am sure that this creativity has been good therapy; a distraction for the mind and physiotherapy for the body one day at a time...



Sandra E Ball

United Kingdom

Title of creative work: "Yonder – Talla Water in the Scottish Borders"

Medium: Watercolour

I underwent surgery to remove a rare form of brain tumour, vestibular schwannoma, in May 2011. "Yonder", a watercolour of Talla Water in the Scottish Borders, was inspired by the first break away - as soon as the COVID rules allowed - to see our eldest son and granddaughter. It was May 2021 when we made this trip and I captured a photograph from the car window for reference. It was such a peaceful spring day with the sun coming out to create the light and shadows I tried to depict. This is a big painting for me, 14" x 21" which I created in watercolour using an upright easel. It was a challenge as it is not my normal way, I usually have my paper on a board with a slight incline for the paint to run downwards, often creating the first washes with the board flat. I used some visioneering in the process trying to simplify the painting yet still showing a realistic landscape with some depth.

मतलब

कलम उदास रहती है, आजकल,
कह रही थी,
"अब मतलब के सिवा, कोई लिखता ही नहीं..!"

मैंने कहा,
"वो बेमतलब का लिखेंगे तो चलेगा!?"

हँसते-हँसते, कहने लगी,
"मैं चाहती हूँ, के लोग बस,
मतलब के लिए लिखना छोड़,
मतलब का लिखने लगें...
ये घर, गाँव, शहर, देश, ये जहाँ,
सारा, खुद-ब-खुद संवर जाएगा।"

"काश के, मतलब का मतलब, लोग समझ पाते।"

- ब्रिजेश देशपांडे 'वारिस'

Significance

My pen seemed sad for the past few days she said,
"Everyone writes so shallowly these days!"
Wittily, I said,
"So, you want them to write deep, ha?" She laughed and said,
"What I wish is not to write shallow, write contextual and be significant",
You'll see the whole world will start falling into place,
Everything around will start falling into place,
"How I wish, they knew, what being significant really meant?"

Brijesh Deshpande

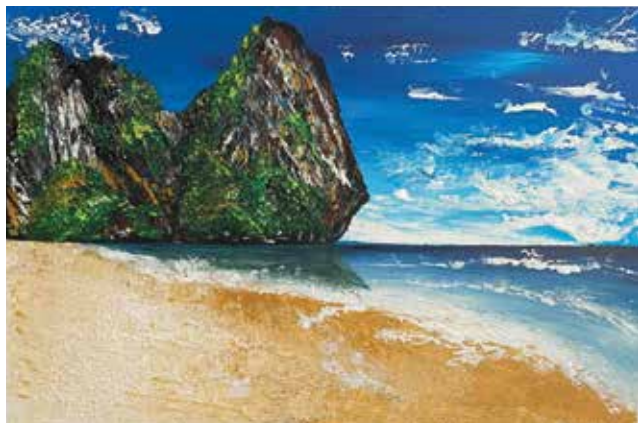
India

Title of creative work: "Significance"

Medium: poem

I was diagnosed with a brain tumour four years ago. Poetry is a passion of mine. I write in Hindustani, a combination of Hindi and Urdu. I would like to create more awareness of brain tumours and spread the word amongst youngsters and help heal a lot of patients suffering from brain tumour and the dreaded monster 'cancer'.

Fighting with any such thing is easy, in my opinion. It just requires two things: a positive attitude and humongous conviction. As for the rest, everything will automatically fall in place.



Sharon Carter

United Kingdom

Title of creative work: "Peaceful Place"

Medium: acrylic paints on canvas

I have been a brain tumour patient for two years. I have an intracerebral plasma cell granuloma deep in my brain that is inoperable. I have had plasma exchange, rituximab therapy, seven months of chemotherapy and I just finished radiotherapy. Nothing to date has improved the tumour. In this time I have had to retire from my 32-year career as a nurse due to the problems it has left me with. I have a great family and continue to remain positive for the future and hope to stay as I am if not to improve. I suffer with headaches, spatial awareness problems and memory problems. Painting is something I do to relax.

My painting is of a place to think, feel and breathe.



Jaya Pal

India

Title of creative work: "The Lord Shiva"

Medium: painted paper

This is the symbol of an Indian God that represents Lord Shiva in Hinduism. As the most powerful of deities, temples are built in his honour in India.

I am 18 years old and was diagnosed with a brain tumour in 2020 with symptoms of headache and seizures.



Yaron Butterfield

Canada

Title of creative work: "The Elephant and the Camel"

Medium: acrylic on canvas

The brain cancer I was diagnosed with, GBM, has affected me in many more ways than I ever would have thought, positive and negative... During treatment, I had a dream. In front of me were a few stalls, like where horses are held and I stood at one of them. There was an elephant facing me. He was calm with a very peaceful look and then he began to flicker into a camel. Now I was facing a camel who stood in front of me just as calmly as the elephant. Then it morphed back to an elephant. Then back to a camel. The cycle continued and I then heard a deep voice that seemed to come from above telling me that everything would be fine. The next day I researched how to interpret a dream of an elephant. "Positive, a request has been heard." Then, I looked to see what it said about a camel: "Saved from death." I was convinced that this was a message from a higher source. My website is <http://yaronbutterfield.com>



Audrey Thibeau

United States

Title of creative work: "Lila Thinks"

Medium: acrylic wool on monks cloth using a loop pile tufting gun

My glioma has brought me through a few horrific surgeries and eventually chemo and radiation. My beautiful brain has told itself how to re-learn to talk and read, and gains to work on its short-term memory day by day.

My brain is so powerful it creates wonderful people to produce beautiful art out of thought and consideration. This lovely piece is done by Lila Khan and is a wonderful gift for me.



Suhani Rajput

India

Title of creative work: "Meaningful 2"

Medium: papercraft

I [am 16 and] was diagnosed with a craniopharyngioma which impacts my emotions, well-being, quality of life and physical health. It also impacts my family life as well as my studies.

These flowers are made up of paper and they are arranged in a circle. These are also used in Indian festivals for decoration like Duwali, Dussehra etc.



Giuseppe Raschiani

Italy

Title of creative work: "Bright Energy"

Medium: acrylic on canvas and vinavil

I had an attack of epilepsy at Christmas 2020. Suddenly, in the hospital after an MRI I was told that I had a brain tumour that was likely glioblastoma at stage IV. I had brain surgery in less than five days later then I began a standard treatment plan with radiation and chemotherapy. Today, I feel good overall. I have so many moments where I get to enjoy life with my family, my son and my friends.

These paintings are an expression of my energy that manifests itself in colours and shapes. The title says the meaning. It is energy that gives light, well-being, positivity, good humor and love. I give you the energy of my brain and my love. I love living.



Cathie Short

United Kingdom

Title of creative work: "Our Jack Russell 'Charlie'"

Medium: pastel on paper

My eldest daughter has been diagnosed with a brain tumour this year in May, with a grade 3 anaplastic astrocytoma. She had two emergency operations in May and has undergone radiotherapy and now started chemotherapy. It has been a worrying time but as a family we work together and have a shared interest in art and painting.

This is an original painting of our Jack Russell - Charlie.



Yaron Butterfield

Canada

Title of creative work: "Our Beautiful Genome"

Medium: acrylic on canvas

The brain cancer I was diagnosed with, GBM, has affected me in many more ways than I ever would have thought, positive and negative. I see the beauty in so many things. In my role in genomics, I analyze DNA sequence data from cancer patients to help find disease causing mutations and chromosomal alterations related to specific cancers. Having been through my own cancer journey and being aware of certain mutations that can affect prognosis, I came up with this piece of art. There's a simple beauty in DNA and how changes in its structure can lead to disease. My website is <http://yaronbutterfield.com>



Ellen Yates

United Kingdom

Title of creative work: "Cushions"

Medium: crochet

I was diagnosed with an acoustic neuroma in April 2015. Since that time, I have regular MRI scans. I suffer from tinnitus, balance issues, anxiety/depression, brain fatigue/fog, memory loss to name a few of my symptoms. But crochet helps me 'zone out' and be in the moment.

I was asked to crochet two cushion covers of a wildflower meadow, using various shades of gold, cream and yellow with a dragonfly, bee and butterfly. I decided on Spring/Summer and Autumn/Winter as themes. I edged both cushions in the same colour and both have the same wooden fence. I did a lot of research beforehand into flowers, etc.



Wow Warli by Megha

India

Title of creative work: "Contemporary Imaginary Bird"

Medium: hand painted on handmade paper with acrylic colour

This is a contemporary art form. I was once travelling by train and saw a leafless tree through the train window and there my imagination took over, then it turned into this beautiful painting.



Leon Muzadzi

Zimbabwe

Title of creative work: "Païda" and "Love and Hope"
Medium: charcoal pencil

My name is Leon Muzadzi. I'm 19 years old and I live in Zimbabwe. I am a volunteer with the Zimbabwe Brain Tumour Association (ZBTA). I am currently retaking my Advanced Level studies after the delays caused by the COVID-19 virus pandemic. I volunteered to draw a picture of Païda Mungoshi from a portrait and I also drew two dolphins doing a happy leap in the water depicting a heart shape over the rising sun. The rising sun symbolises HOPE whilst the heart shape symbolises LOVE.

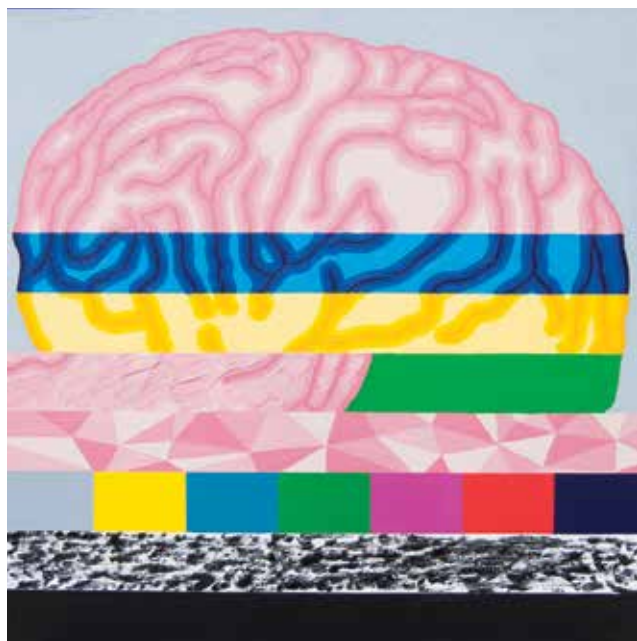
Païda's mother, Christine Mungoshi, said: "Païda would have turned twenty-nine this year. She was always bubbly, even when things were not so rosy. It was only when her illness became much worse that the brightness in her eyes dwindled. Païda lost her battle to a brain tumour after a five-year fight when she was twelve. She fought with both bravery and naivety.

During the early onset of her illness, Païda was given a dolphin snow globe by a family friend, and she was blown away by the dolphins. She loved everything about dolphins such as pictures and videos.

Just recently, we were discussing about this with a young Zimbabwe Brain Tumour Association (ZBTA) volunteer, 19-year-old Leon Muzadzi, and the idea of the drawings was born. Leon is an upcoming young Zimbabwean artist.

When I saw the pictures, tears came flooding into my eyes. I felt both pain and joy. Memories flooded back after seeing the picture of Païda with a shy smile on her face, next to the awesome picture of Païda's favourite animal, depicting love and hope symbols. I feel both LOVE and HOPE are forever.





Nick Dawes

Australia

Title of creative work: "Brain II"

Medium: oil on canvas.

'Brains' was a series completed in 2014 as a part of my year 12 VCE Art portfolio submission. The series focused on my older brother Connor who passed away in 2013 from an ependymoma brain tumour. The works in the series explore his battle with brain cancer, depicting his struggles and anguish in a bright contradictory tone reflecting his personality throughout his journey.

'Brain II' depicts Connor's battle with brain cancer in a series of horizontal bars. Connor's healthy brain transitions through different phases of disruption until it is unrecognizable and glitched to black.



Lynda Tse

New Zealand

Title of creative work: "Hydrangea the Fairy"

Medium: wooden clothes peg, fabric, diamantes and other decorative materials

In 2006 I was diagnosed with a glioblastoma (GBM). Designing and crafting these small peg dolls played a huge part in my healing process. I was able to focus on creating these little characters which I collectively called "Peglets"...I have found making peg dolls a way of escaping the harsh reality of having a brain tumour. However, I am lucky to be here and in good health, other than a few issues with my balance which the neurologist has put down to long term radiation effects...Peglets are wooden peg dolls which I design and hand-craft in Wellington, New Zealand.

मेरा फैसला...

क़ज़ा ने चुपके से क़ानों में कहा,
"चल संग मेरे, एक नयी ज़िन्दगी दूँगी तुझे"

उधर हयात फुसला रही थी, कहती थी,
"बची बसर खुशनुमा कर दूँगी तेरी"

मैंने दोनों का हाथ छोड़ा और कहा...
"बेवफ़ा हो तुम दोनों! बिना तुम्हारे,
मैं खुद ही खुशी ढूँढ लूँगा।"

सन्नाटे के एक लंबे वृक्ष बाद,
वो दोनों मेरी ओर बढ़ीं,
मैंने बंद आँखों से,
हाथ के इशारे से रोका उन्हें

और कहा...
"दरवाज़ा तुम्हारे पीछे है।"

- ब्रिजेश देशपांडे 'वारिस'

My Verdict...

In my ears, Death whispered,
"Come with me, I'll get you
a new life"

Far away, Lifeline was convincing me,
"Stay, I'll mould the remainder, graceful"

I let go of both and said,
"Betrayers! No need of any of you,
I'll find happiness beyond you"

A long moment of silence,
Both seemingly hailed towards me,
With eyes shut and silent gesture of the hand,
I stopped them both, and said,

"Please, the 'Exit' is behind you!"

Brijesh Deshpande

India

Title of creative work: "My Verdict"

Medium: poem

I was diagnosed with a brain tumour four years ago. Poetry is a passion of mine. I write in Hindustani, a combination of Hindi and Urdu. I would like to create more awareness of brain tumours and spread the word amongst youngsters and help heal a lot of patients suffering from brain tumour and the dreaded monster 'cancer'.

Fighting with any such thing is easy, in my opinion. It just requires two things: a positive attitude and humongous conviction. As for the rest, everything will automatically fall in place.



Rebekah Bagguley

United Kingdom

Title of creative work: "Joy"

Medium: acrylics

I was first diagnosed with an astrocytoma, grade 2 in my frontal lobe in 2005, aged 27. I was fortunate to have surgery which removed almost all of the tumour and my recovery was almost complete apart from fatigue and bouts of depression. In 2011 the tumour progressed into a cancerous anaplastic astrocytoma (grade 3) and my life was almost completely changed again. Painting helps me to live with these changes and appreciate the world around me.

This piece was painted for a wonderful, supportive friend who loves horses. I wanted it to be colourful, bold and full of energy. It energises me to look at it and I like to think of the horse being free and full of joy.



Tricia Ann Roloff

United States

Title of creative work: "Tahiti Days II"
Medium: coloured photographic image

The trip I would've taken. After surgery I just wanted to go lay on a beach, but alas I had to go back to work. I believe recovery time is very important!



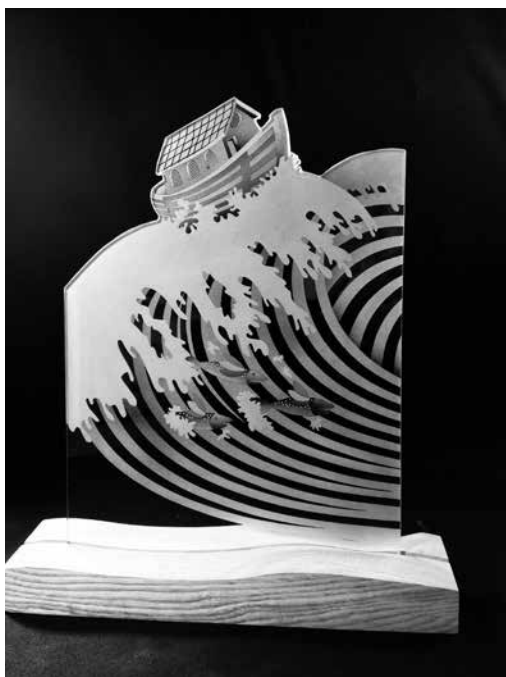
Jaya Pal

India

Title of creative work: "Ganesha"
Medium: paint/pen on paper

Ganesha is an Indian God, and is one of the most important Gods in Hinduism. Ganesha is highly recognisable with his elephant head and human body, representing the soul and the physical.

I am 18 years old and was diagnosed with a brain tumour in 2020 with symptoms of headache and seizures.



Jan Watson

United Kingdom

Title of creative work: "Noah's Boat"

Medium: sand carved glass

Before my craniotomy my neurosurgeon informed me to be prepared that I may not be able to return to working as a stained glass artist with my wife, Dawn, in the business we started together. Little steps at a time and a lot of support from Dawn and we are functioning as a team again although a little slower than before. Yes, the world of stained glass can be hectic at times.

I have always been fascinated by the movement of the seas. My ancestors were master mariners and I have always wondered how they endured the constant roll of the wind and waves.



Kate Winters

New Zealand

Title of creative work: "Sunshine Tui"

Medium: oil on canvas

My son, Ben, was diagnosed with a grade four glioblastoma in May 2017. He was given two years to live and no hope for a future. With his positive attitude, he has fought the odds, his brain scans are still clear and he is still out there taking beautiful photos.

This painting, oil on canvas, is based on a photo taken by my son, Ben. It represents a cheeky New Zealand bird enjoying life in the sunshine, just as Ben is with his beautiful family, more than four years after his devastating diagnosis.



Suhani Rajput

India

Title of creative work: "Meaningful 1"

Medium: papercraft with beads and mirrors

I [am 16 and] was diagnosed with a craniopharyngioma which impacts my emotions, well-being, quality of life and physical health. It also impacts my family life as well as my studies.

My creation is a paper flower, made up of colourful paper with decorative materials like beads, stones etc. It is used as decoration during festivals and other functions like marriages, etc.



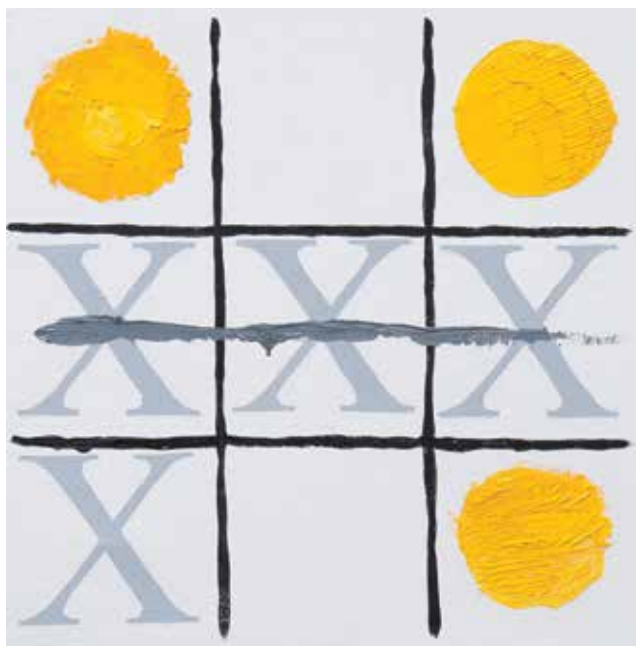
Wow Warli by Megha

India

Title of creative work: "Dancing Scene in Warli"

Medium: hand painted on a wall with acrylic colour

With dancing elephants and dancing Warli tribes, this artwork depicts festivities and celebrations.



Nick Dawes

Australia

Title of creative work: "Tic Tac Toe"

Medium: oil on canvas

'Brains' was a series completed in 2014 as a part of my year 12 VCE Art portfolio submission. The series focused on my older brother Connor who passed away in 2013 from an ependymoma brain tumour. The works in the series explore his battle with brain cancer, depicting his struggles and anguish in a bright contradictory tone reflecting his personality throughout his journey.

'Tic Tac Toe' depicts Connor's battle with brain cancer as a simple kid's game. Connor plays as the Os in his favourite colour of yellow where his brain tumour are the Xs in grey, the symbolic colour of brain cancer. The work aims to summarise his battle through the medium of one of our favourite games as small kids growing up.



Lynda Tse

New Zealand

Title of creative work: "Merlin the Wizard"

Medium: wooden clothes peg, fabric, leather and other decorative materials

In 2006 I was diagnosed with a glioblastoma (GBM). Designing and crafting these small peg dolls played a huge part in my healing process. I was able to focus on creating these little characters which I collectively called "Peglets"...I have found making peg dolls a way of escaping the harsh reality of having a brain tumour. However, I am lucky to be here and in good health, other than a few issues with my balance which the neurologist has put down to long term radiation effects...Peglets are wooden peg dolls which I design and hand-craft in Wellington, New Zealand.



Rebekah Bagguley

United Kingdom

Title of creative work: "Waiting for the Hare – Bus A320"

Medium: acrylics

I am a 16-year survivor of brain cancer and was first diagnosed at 27. I recovered from the surgery and treatment almost completely after seven years but then discovered it had returned as a grade 3 anaplastic astrocytoma. My hopes for my future career, to become a mother, to live independently disappeared and I have had to rethink and adapt my life post treatment with fatigue, huge weight gain, depression, and anxiety. I have found real pleasure in painting as it helps me to appreciate the world around me and freshen my mind...

में और तू

सब को बचाने वाला एक है
मुझको मैं और तुझको तू
सब को दिखने वाला एक है
तुझको मैं और मुझको तू
सब को नचाने वाला एक है
मुझको मैं और तुझको तू
सब में बसने वाला एक है
तुझमें मैं और मुझमें तू

- ब्रिजेश देशपांडे 'वारिस'

Me and You

There's one who can save us all,
For me it's me and for you it's you.
There's one who will be seen in all,
For you it is me and for me it is you.
There's one who makes us dance in all,
For me it's me and for you it's you
There's only one who resides in us all,
In you, it is me and in me, it is you.

Brijesh Deshpande

India

Title of creative work: "Me and You"

Medium: poem

I was diagnosed with a brain tumour four years ago. Poetry is a passion of mine. I write in Hindustani, a combination of Hindi and Urdu. I would like to create more awareness of brain tumours and spread the word amongst youngsters and help heal a lot of patients suffering from brain tumour and the dreaded monster 'cancer'.

Fighting with any such thing is easy, in my opinion. It just requires two things: a positive attitude and humongous conviction. As for the rest, everything will automatically fall in place.



Suhani Rajput

India

Title of creative work: "Meaningful 3"

Medium: Mehndi design

I [am 16 and] was diagnosed with a craniopharyngioma which impacts my emotions, well-being, quality of life and physical health. It also impacts my family life as well as my studies.

This is a Mehndi design which is very popular in India. It is a very important ritual during marriage as the bride and other girls apply on their hands.



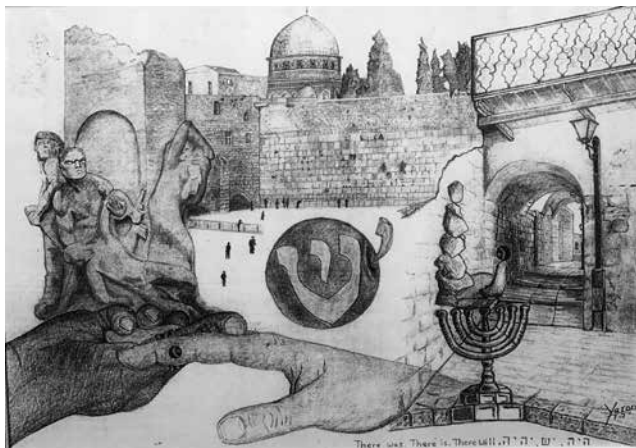
Daxa Lad

United Kingdom

Title of creative work: "Colourful Brain"

Medium: flowers and oasis

I was diagnosed with schwannoma in 2013, and since then I have had six neurosurgeries... After all these surgeries I have been through part of my brain has given me creative skills such as designing cards, making jewellery and doing flower arranging, the one creativity I love most. In 2019 my son and I gave a presentation at a brain tumour event in the UK which was organised by Brain Tumour Support. I had an idea to use parts of the brain and build it up like a jigsaw using colourful flowers and joining the parts as one brain... We had a workshop organised with six groups of people. Each group was given oasis in the shape of a brain part. When all the parts were completed, we joined them like a jigsaw and made them into one brain.



Yaron Butterfield

Canada

Title of creative work: "Time – There Was, There is, There Will"

Medium: pencil on paper

The brain cancer I was diagnosed with, GBM, has affected me in many more ways than I ever would have thought, positive and negative. One thing that gave me strength to heal from the horrible brain cancer was thinking of past moments where I was strong, full of energy, experiencing love and all the beauty I was exposed to. [In this picture] above the big hand on the bottom a man is falling looking down, a strong man is holding him and looking forward, and man behind/beside him with a dagger is looking up. Sometimes I imagine I am all three people at different stages in time. Once I was falling (the past, when I got cancer), I grabbed myself and tried to be strong (the present), and I moved forward, looking ahead and upwards (the future).



Carol Currie and Stu Leggett

Canada

Title of creative work: "Killarney Tree"

Medium: bas relief sculpted painting

I was diagnosed with a brain lesion in 2013... As the disease has progressed, my increasing right-sided weakness and violent right hand tremors have eventually led to the complete abandonment of my dominant right hand and the subsequent switch to become an entirely left-handed painter...Through years of struggle and determination, my husband Stu Leggett and I have combined our love for each other with our artistic passions, reinventing ourselves and resuming our position within the art world...A video of my story can be found on YouTube - <https://www.youtube.com/watch?v=DQMDbYdCmUc>



Colin Oliver

United Kingdom

Title of creative work: "LeGo® Car - Post Op"

Medium: plastic LeGo® pieces

Colin's parents, Kathy and Gordon Oliver, said: "Colin was diagnosed with an astrocytoma brain tumour in 2004, age 24. Following neurosurgery, he wanted to exercise his newly-operated-on brain as well as test his dexterity and hand-to-eye coordination... So he asked for some LeGo® to be brought to hospital to see whether he could still fit together the very tiny plastic bricks and plastic accessories. Colin laboured over this little LeGo® car for some time but was finally able to put it together. This little car represented a real triumph and hope for Colin, and he kept it on a shelf in his bedroom until he passed away, age 32, in 2011."

Full copyright of the design of this plastic car is acknowledged to belong to LeGo® and not to the late assembler of the item.

*"The aim of art is to represent
not the outward appearance of things,
but their inward significance."*

Aristotle (384-322 BC), Greek philosopher and polymath



In 2021, the **International Brain Tumour Alliance (IBTA)** launched “**Brilliance!**”, its inaugural exhibition of creative works from the global brain tumour community.

This event aimed to shine a brilliant light on the inspiring creativity and diversity of the international brain tumour community. As you have seen in the previous pages of the 2021 exhibition catalogue reproduced in this year’s *Brain Tumour* magazine, our community did not disappoint.

The IBTA was overwhelmed by the enthusiastic response from patients, family members, friends, and healthcare professionals around the world who shared so many beautiful and moving works of art that included paintings, drawings, sculptures, glasswork and more. The beauty of the artworks speaks for itself, and the diversity, courage and strength of the international brain tumour community is truly inspirational.

We would like to thank each and every one of our Brilliance! 2021 artists who have contributed to such an amazing collection of creative works.

With the wonderful success of “Brilliance!” in 2021,
the IBTA is very pleased and excited
to announce the launch of:



BRILLIANCE! 2022

A Second Virtual Exhibition of Creative Works from the Global Brain Tumour Community

Patients, family members, friends, researchers and healthcare professionals of every discipline are once again invited and encouraged to submit their work to “Brilliance! 2022”.

Submitted works can include pieces created especially for this exhibition, but may also include artwork created previously by eligible participants.

To view the complete guidelines and instructions,
along with the official submission document,
please visit www.theibta.org

The deadline for submissions is September 30, 2022.

1992  2022
 Association pour la Recherche sur les Tumeurs Cérébrales

30 years already !

The ARTC (Association for Brain Tumour Research) founded by physicians and patients' relatives is celebrating its 30th anniversary in 2022.

It supports basic as well as clinical research in the area of neuro-oncology and helps the hospital services taking care of patients suffering from brain tumours.

Its contribution extends to :

- Attributing research grants to labs for research projects and fellowship scholarships ;
- Supporting educational program for caregivers ;
- Improving hospital welcoming conditions for patients.

It has delegations in the different regions of the country at its disposal to relay its actions.

contact@artc.asso.fr
 Association pour la Recherche sur les Tumeurs Cérébrales
 Groupe Hospitalier Pitié-Salpêtrière
 Division Mazarin
 47-83 boulevard de l'Hôpital 75013 PARIS - FRANCE
 artc.asso.fr


 **Il Laboratorio di Chiara**

The association "Il Laboratorio di Chiara" was born in memory of little Chiara.

The aim of the organization is mainly to create awareness about pediatric neuro-oncologic diseases and to raise funds for research. Our mission is to fund scientific research projects which will study ways to prevent and treat infantile brain tumors, especially medulloblastoma. For this reason, our center is accredited by Bambino Gesù Pediatric Hospital in Rome. For more information about the projects that will be funded through this program, we invite you to visit our website.

Little Chiara used to say "Your heart is inside mine!". If you want, you can take her words and make them yours. Unite your heart to ours and...give wings to hope!

WWW.ILLABORATORIODICHIARA.ORG



A FOUNDATION OF HOPE - SINCE 1995

SOUTHEASTERN BRAIN TUMOR FOUNDATION

Devoted to funding a cure for brain tumors and providing support and outreach to patients and their families.

The SBTF is a 501 (c)3 not-for-profit organization and a public charity based in Atlanta, GA, USA

WWW.SBTF.ORG.

 **ILAM**
 The Israeli Brain Cancer Association

ILAM has published a digital booklet on rights for patients in Israel with glioblastoma (GBM), including recent changes for improved benefits for GBM patients and their families

For more information:
www.ilam.org.il

Dr. Keren Gonen, CEO of the Association:
 "I am proud to advance changes for the benefit of patients and I am grateful for the cooperation with the National Insurance Institute of Israel for the willingness to take action to better the quality of life for patients in general and GBM patients in particular."

 Dr. Keren Gonen, CEO of ILAM

 Meir Shpigler, NII Director General

Mirroring life with a brain tumour

Karen Risgaard, Hanne Lisby and Pia Riis Olsen
The Danish Brain Tumour Association



"The films make me remember and bring back memories of unsolved problems that I realize I need to face now." (a brain tumour patient)



Karen Risgaard



Hanne Lisby



Pia Riis Olsen

Many patients and their relatives are emotionally moved watching the films we created and they tell us that we have managed to capture their lives and that they completely recognise the situations displayed.

In September 2021 we (The Danish Brain Tumour Association, HjerneturmorForeningen) released nine short films on our webpage about the impact a brain tumour can have on a family. From members of our Association we had experienced a huge need for understanding of their environments and about the consequences of living with a brain tumour.

Therefore, we produced the films to enlighten people and raise general awareness of the impact of life with a brain tumour – and additionally increase knowledge especially among politicians,

healthcare professionals, general practitioners, job consultants, colleagues, and newly diagnosed patients and their relatives. Being a small patient organisation with about 280 Danish members, we needed to create something extraordinary and hoped that visualising the issue might catch people's attention and make them better understand.

We chose to focus on a patient with a low-grade brain tumour, as we have experienced their situation to be hugely challenging during survivorship over many years. They are expected to continue their

everyday life as before and return to the same jobs. Many friends, colleagues etc. have expectations that the patients can rarely meet.

In the films we follow "Lotte" from the night she wakes up with an epileptic attack, through examinations and an operation to the problems that arise when she is expected to return to a demanding job. Nobody understands that Lotte is challenged and that her brain is affected by the operation. Lotte's husband and daughter also experience huge changes in their lives due to Lotte's brain tumour.

Films about brain tumor

The Danish Brain Tumor Association has produced nine short films about getting and living with a brain tumor diagnosis. It is our hope that the films will help family, friends, and professionals to better understand brain tumor patients.

Et forandret liv - A changed life
2021 | 9 episodes



1. A happy family
Episode 1 | 2:46

In an instant, Lotte's life is completely changed. For a long time, she has been worried and consulted her doctor several times, but now it is clear that something is completely wrong. No, it wasn't "just stress" - it turns out to be a brain tumor! Then suddenly her symptoms of headache, vision disorder, concentration difficulty and memory loss make sense.



2. The operation
Episode 2 | 2:43

Lotte and her family are thrown into uncertainty due to the operation, and Lotte thinks: "What's left of ME after the surgery"? This concern is shared by her daughter Freja and husband Dan, who already notice at their first visit, that Lotte is not sensing her left side, but she shrugs it off. Lotte IS changed.



3. The message
Episode 3 | 2:18

After Lotte's brain surgery, she and husband Dan have an appointment with the neurosurgeon. They are going to get the results of the biopsies and talk about prognosis and the further course related to Lotte's brain tumor. Will they get the answers they have been hoping for?



4. A new daily life
Episode 4 | 2:20

After the surgery, Lotte and her family try to get back to everyday life, but great demands are made on both Lotte, her husband Dan and their daughter Freja. Lotte is tormented by guilt towards her daughter and husband - and at the same time it requires tremendous patience and understanding on their part.



5. Back to work
Episode 5 | 2:48

Lotte has a meeting with her boss at work, where her colleagues are looking forward to her return. The colleagues' expectations collide with Lotte's powerlessness in not even being able to read what it says on the welcome cake. All involved are completely unprepared for this situation.



6. Freja's party
Episode 6 | 3:07

Finally, Freja can allow herself to be young and have friends over for a party when her parents are out. But her happiness is short-lived - Lotte returns home early and the party is disrupted. Freja gets caught in a dilemma between consideration for her friends and her mother.



7. Casework
Episode 7 | 2:55

After Lotte is dismissed from her job, which she can no longer manage after her brain surgery, she is invited for an interview at the municipal job center. Lotte has prepared a list of job proposals, but it turns out that the caseworker has completely different expectations to Lotte's future job seeking.



8. The family support group
Episode 8 | 3:12

Lotte's husband Dan carries a great burden after Lotte's brain surgery and its consequences. To share his frustrations, Dan attends a meeting in one of the Brain Tumor Association's support groups, where he meets other relatives of brain tumor patients. Here all thoughts and feelings are welcomed, and the mutual acceptance and understanding is profound.



9. Talk about it
Episode 9 | 2:19

It's been a few years since Lotte's brain surgery. The tumor has had major consequences, and Lotte has had to acknowledge that she is a changed person. But they have learned to talk about it and realized that openness has brought more peace. Their hope for a new life together has been fulfilled.



HJERNETUMORFORENINGEN
hjernetumorforeningen.dk

We want to tell people that there is a life to live, though a family member's brain is affected by the tumour and its treatments. Our main message is in fact that it is important to talk about what happens. To live with a brain tumour, there must be understanding and acceptance from people around the patient and the family.

To illustrate a realistic picture of Lotte's life, we chose to cooperate with The School of Actors Ophelia. Therefore, all roles in the films are played by student actors. The instructor interviewed several patients and relatives before he wrote a manuscript, which we in our Association subsequently prepared thoroughly with him. The COVID pandemic threw a spanner in the works as we were not allowed to enter any hospital to film important scenes. So, our films were delayed - but they were worth waiting for!

We celebrated the release of the films in a cinema in Copenhagen, where all nine videos were combined into one film, so the audience could have a full experience of the messages in the films. Afterwards, we had a lovely reception with members of our national Brain Tumour Association (HjernetumorForeningen), the actors in the films and healthcare professionals.

During the following weeks, the films were presented one by one on our Association's webpage. In connection with the films, we drafted short articles about the issues and challenges shown in the nine films, and we also referred to research on the chosen topics.

Finally, we added subtitles to the films in English to make them understandable to an international audience.

The project involved massive work for us over many months - not only because of the pandemic. It was necessary to cooperate with a professional company to get the permissions and appointments. As the manuscripts were created, it became clear that there were two very different approaches which should be combined in the films. On the one hand, our Association had a clear requirement for clarity and authenticity regarding the tumour, the symptoms, the operation etc and on the other hand, the film company had a professional idea of a good story, capturing pictures etc. But finally the manuscripts were ready and the production could be planned. ➔

Many things and details had to be organised and the actors had to familiarise themselves with life affected by a brain tumour. The actress who played Lotte had several meetings with patients so she could be acquainted first-hand with the challenges and deliver an authentic performance regarding the cognitive impairments following a brain tumour diagnosis.

The production was quite expensive (Euros 68,000). It was only possible because we had supplementary funding. To our great delight we have had much positive feedback

from people who have watched the films and we have observed an increase in the numbers of members of our Association.

We hope this article and our films will inspire some of you! ■

You are welcome to be in touch with us for further information about the project. Please contact: Hanne Lisby, Vice Chair, HjerneturmorForeningen, at hanne@hjerneturmorforeningen.dk



To view the films on our website, please visit:


<https://www.hjerneturmorforeningen.dk/fakta-om-hjerneturmor/film/>

or you can watch our videos on YouTube: [Hjerneturmorforeningen](https://www.youtube.com/Hjerneturmorforeningen)

Don't miss the IBTA's new podcast series, "A Brain Tumour and Me"


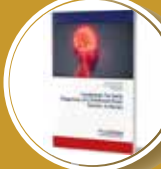

In the IBTA's podcast series, "A Brain Tumour and Me", we bring you inspirational, moving and personal stories from the international brain tumour community as we meet some of those working in the field of neuro-oncology, the people who support patients and their families and those who've been told they have a brain tumour. We learn how brain tumours affect all of these people, often in surprising and unexpected ways.

"A Brain Tumour and Me" is available via Apple Podcasts, Google Podcasts, Spotify, CastBox, Anchor and the IBTA website at www.theibta.org/podcast



BRAIN TUMOUR ASSOCIATION OF KENYA
United to Fight Brain Tumours.

BRAIN TUMOUR ASSOCIATION OF KENYA (BTAK)

VISION
A country where all brain tumour patients receive quality healthcare, patients and caregivers are well informed and supported.

MISSION
To promote delivery of quality healthcare for brain tumour patients. We also aim to provide information, support and to advocate for brain tumour patients and their caregivers in Kenya.

PILLARS

- ① To promote quality, accessible, and affordable healthcare for brain tumour patients.
- ② To engage in advocacy, creation of awareness and dissemination of information on brain tumours.
- ③ To support Research, education and innovation in management of brain tumours.

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🌐 www.btak.org
✉ info@btak.org
📍 BMA Center, Main Road, Nairobi, Kenya 201



JAPAN BRAIN TUMOR ALLIANCE

NPO法人脳腫瘍ネットワーク (JBTA) は、全国の脳腫瘍患者とその家族を支援するために、脳腫瘍患者・家族、医療関係者、福祉・教育その他の関係者の力を結集したネットワークの構築を目標に活動しています。

OUR AIM: SUPPORT PATIENTS WHO SUFFER FROM BRAIN TUMOR AND THEIR FAMILIES

OUR ACTIVITIES
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<http://jbta.org>

Brain Tumour Foundation of Canada Welcomes New CEO

Maureen Daniels, BScN, RN, Coordinator, The Gerry and Nancy Pencer Brain Tumor Centre, Princess Margaret Cancer Center, University Health Network and IBTA Senior Advisor
Toronto, Canada

BRAIN TUMOUR FOUNDATION OF CANADA (BTFC) is the only national brain tumour organization offering education and support to patients and families affected by a brain tumour in Canada. The organization's vision - "To find the cause of and a cure for brain tumours while improving the quality of life for those affected" is at the core of all that BTFC does. Now, as they celebrate their 40th Anniversary, the winds of change are gently blowing at BTFC. On February 28, 2022, the Foundation was pleased to introduce their new CEO, Shannon LaHay. Just a month into her new position, Shannon connected with the IBTA to reflect on some first impressions and share her excitement and positive energy as she gets to work.



Roles and responsibilities

As she begins her new role Shannon explained that she is very mindful of the great responsibilities that go with her position. She sees her primary responsibility to the brain tumour community - patients, caretakers, survivors and families - as ensuring that BTFC continues to provide the support, information and resources that are the hallmark of the organization.

She also plans to focus on advancing the Foundation's mission, vision and values, with a view to contributing to an end to brain tumours. That means supporting and advocating for research into the causes of and potential cure for brain tumours and bringing hope to the brain tumour community. ➤



Shannon LaHay, the recently appointed Chief Executive Officer of Brain Tumour Foundation of Canada

Shannon reflects that the responsibility to support her team is one she takes very seriously as well. She said: “The Brain Tumour Foundation of Canada has a deeply compassionate and committed team of staff and volunteers. I’ve been welcomed with open arms and hearts and I’m humbled to support them in their work.”

While her new position at BTFC is Shannon’s first affiliation with the brain tumour arena, she is no stranger to the not-for-profit field. When asked what drew her to this kind of work she responded: “To be honest, it wasn’t a conscious decision to specifically go down a career path in the not-for-profit sector. I had an opportunity to make a move that was right for my life and my family at the time. But once I was in that role, what I discovered was purpose. The deeply satisfying feeling of making a difference. That was when I decided that the not-for-profit sector was where I belonged, specifically in advancing healthcare and wellness.”

Shannon’s past roles as Director of Development and Partnerships with The Sunshine Foundation of Canada, and as Executive Director with The Alexandra Marine and General Hospital Foundation have enhanced her skills in operations and strategic planning, engaging and fostering partnerships locally and at the national level, and leading a team to achieve organizational goals.

Learnings from the brain tumour community

Now, as she becomes acquainted with the brain tumour arena Shannon is eager to share her first impressions.

“I have quickly learned that the brain tumour world is incredibly complex,” she said. “Even more so because at the Brain Tumour Foundation of Canada we serve the needs of Canadians affected by both malignant and non-malignant brain tumours. What has already become very evident to me is that clinicians, researchers, and advocates in the brain tumour arena are incredibly dedicated and passionate. Thankfully, we are not approaching this alone. We have many partners, including the IBTA, that we are able to collaborate with to bring positive change and to continue to foster hope. I have also quickly realized that brain tumour awareness and advocacy

requires far more attention to provide the needed treatments, access to care, and support for patients, survivors, caretakers and families on their journey.”

Shannon goes on to reflect that: “My work has always brought me tremendous satisfaction, in particular the incredible connections and authentic relationships that I’ve been able to build through my work. Being connected with others to effect meaningful change and witness positive impact is powerful. I can’t think of another career path where I would have had the opportunity to build the close relationships that I have over the years and know that I am part of helping to make a positive impact on the lives of those I serve. My short time at Brain Tumour Foundation of Canada, has served to strongly reinforce this view.”

Planning for the future

Moving forward, Shannon is deeply committed to making meaningful change.

She said: “For me the key to meaningful change is knowing that we are doing better than we were before. It really comes down to impact and making a positive difference. On an individual level, it means reaching one more person, providing support or information that helps improve the quality of life for one more patient. As we move the dial in the brain tumour arena, meaningful change means more support for research, and access to care and treatments. Of course, the most meaningful change will be in realizing our shared goal of an end to brain tumours.”

As CEO, Shannon sees the role of BTFC to continue to be a place that the brain tumour community across Canada can turn to for support, information and education.

“I see our role as being a leader in supporting research that benefits our community, whether that is quality of life, causes, treatments, or a cure. And I see our role as being an advocate, a voice, for the needs of our community.”

BTFC in the post-COVID era

Shannon’s arrival at BTFC is timely as the organization, along with the rest of the world, navigates out of the COVID pandemic. She is optimistic.

“I believe that many not-for-profits will face similar challenges in the post-COVID era. We were fortunate because our team

did an incredible job of pivoting to a virtual world quickly and effectively. Our annual Walk season, which is a significant portion of our fundraising, took place just a couple of months after the pandemic started and we were able to successfully go virtual. We were also able to quickly shift support groups to a virtual platform so that our community could continue to connect.

“Our Mission involves reaching every person in Canada who is affected by a brain tumour and as we incorporated additional virtual and digital components into our support, education, and information programs, we were able to reach so many more people. But we also know that many people in our community are ready to get back to connecting in-person.

“So, one of the challenges moving forward, will involve finding the balance that maintains that broader connection across the country while providing the opportunities to safely come together in-person and have that physical sense of connection and community. I believe that because we were able to stay connected and support the brain tumour community [throughout the pandemic], our community has continued to support us in our fundraising efforts. We have come through these last two difficult years together, and I believe that we will continue to demonstrate that resilience, strength and resolve.”

Relaxing and recharging

Maya Angelou wrote: “As you grow older, you will discover that you have two hands, one for helping yourself, the other for helping others.”

With this sentiment in mind, the IBTA was intrigued to know what Shannon does to care for herself.

“I have two daughters, who are absolutely the joy of my life. So, much of my time outside of work is spent with them. My youngest daughter, who is still at home, is an avid horseback rider and we spend a lot of time at the barn or horse shows. My oldest daughter is my world-traveler (pre-COVID) and I look forward to being able to join her on more of her adventures in the future. Being with my loved ones really is my favourite way to relax and recharge.” ■

Hats for Hope

Hats for Hope is a movement to raise awareness for brain cancer in Canada.

Of the 27 people diagnosed with a brain tumour every day in Canada, eight will find out they have brain cancer. Malignant or not, brain tumours are life-altering and treatment options are limited and often invasive.

In 2018, Brain Tumour Foundation of Canada had the House of Commons declare October 24 as the very first Brain Cancer Awareness Day in Canada. It also marked the first Hats for Hope campaign, which saw Canadians put on their hats in support of brain cancer awareness, and post photos on social media with the hashtag #HatsforHope.

Since 2019, Brain Tumour Foundation of Canada has sold thousands of Hats for Hope toques (a warm knitted cap, traditionally made of wool), raising funds as well as awareness for brain cancer. Over the years, the campaign helped reach millions of people on social media including many Canadian celebrities, Olympians, singers and more!

We are looking forward to seeing everyone's posts on **Brain Cancer Awareness Day, October 24, 2022**, and during **International Brain Tumour Awareness Week, October 29 – November 5, 2022!** Help us raise awareness for brain cancer by wearing your hat and spreading hope. ■



Learn more about
Hats For Hope at
www.hatsforhope.ca

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electronic news bulletin.
Visit www.ibta.org



With sincere thanks to Susan Marshall

The international brain tumour community would like to pay tribute to the many years of tireless, dedicated work of Susan Marshall, who led Brain Tumour Foundation of Canada as CEO for almost two decades. Susan's work within the brain tumour community has had a huge impact, not just in Canada, but internationally. She has always been an eloquent, passionate voice for those affected by a brain tumour and as she embarks on her well-earned retirement, the IBTA would like to express our gratitude and heartfelt wishes for her good health and happiness. ■





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Jessica Morris
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1963-2021

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OPTIMUM: a new study of recurrent low grade glioma

OPTIMUM Leadership Team



Elizabeth B. Claus, MD, PhD, is a Professor in the Departments of Biostatistics and Neurosurgery, and Director of Medical Research in the School of Public Health at Yale University. Dr Claus is also Attending Neurosurgeon and Director of Stereotactic Radiosurgery in the Department of Neurosurgery, Brigham and Women's Hospital, Boston, Massachusetts, USA



Roel Verhaak PhD, is Professor and Associate Director of Computational Biology, The Florine Deschenes Roux Chair for Genomics and Computational Biology, at The Jackson Laboratory in Farmington, Connecticut, USA



Bethany M. Kwan, PhD, MSPH is an Associate Professor in the Department of Family Medicine, The University of Colorado School of Medicine, Anschutz Medical Campus in Aurora, Colorado, USA

Lower grade glioma (LGG), a malignant brain tumor, is a disease of young adults for which the optimal treatment remains unknown. This lack of information led Elizabeth B. Claus, M.D., Ph.D., Professor at the Yale School of Public Health and Attending Neurosurgeon at Brigham and Women's Hospital (BWH), to begin the International Low-Grade Glioma (LGG) Registry, a global effort to study adult LGG. To date over 400 people with LGG are enrolled, with participants in thirteen countries (including the United States, France, United Kingdom, Canada, Australia, Hong Kong, New Zealand, Belarus, the Netherlands, Belgium, Germany, India and Spain).

In 2021, the US National Cancer Institute (NCI) awarded funds to the

LGG Registry to study the evolution or progression of LGG over time. The title of the new project is called "OPTimizing engageMent in discovery of molecular evolution of low grade glioma" or **OPTIMUM**. The funding is part of a new National Institutes of Health Cancer Moonshot Initiative called "Patient Engagement and Cancer Genome Sequencing (PE-CGS) Centers." OPTIMUM - led by Dr. Claus along with co-principal investigators (Co-PIs) Dr. Roel Verhaak and Dr. Bethany Kwan - has been named as a PE-CGS Center and includes researchers from the following US institutions: Yale University, The Jackson Laboratory, The University of Colorado, Brigham and Women's Hospital, and Beth Israel Deaconess Medical Center.

What will OPTIMUM do?

OPTIMUM will focus on people with recurrent lower grade glioma. Although the Cancer Genome Atlas (TCGA) and others have identified consequential genetic alterations in primary LGG tumors, the next step is to understand how gliomas evolve overall and in response to treatment. Longitudinal cohorts of glioma patients are fundamental to producing this knowledge. The largest cohort to date (which primarily includes people with higher grade glioma), the Glioma Longitudinal Analysis (GLASS) lead by Dr. Verhaak, showed that glioma treatment is associated with mutational changes that may affect response to additional therapy and outcome.

To better define treatments for low grade glioma the next step is to understand

how these tumors evolve overall and by treatment received. To study this topic, the LGG Registry will partner with 500 adults initially diagnosed with low grade glioma and who have had two or more surgeries for their glioma. We will look to see if genetic changes occur between the first and second surgery and what this might mean for treatment choices.

Learning from OPTIMUM

Participants in the LGG Registry's OPTIMUM study will receive the research findings of these genetic characterizations performed on each tumor specimen and also learn about grouped findings from all participants.

OPTIMUM is trailblazing a new way of doing research and has two main goals based on the following questions:

- 1) How do researchers do a better job at helping people with glioma feel comfortable participating in research projects (PARTICIPANT ENGAGEMENT)?
- 2) How does extensive genetic study of their tumors help people with glioma (GENOMIC CHARACTERIZATION)?

Dr. Claus notes: "Our OPTIMUM team includes patients and care partners who know what it is like to live with a glioma. These individuals and others, including members of patient organizations and institutional review boards, are part of our LGG Research Advisory Council and will help in designing the OPTIMUM research process. We will be testing ideas to improve registry recruitment strategies, such as how research findings will be returned to participants, and if sharing research findings with participants changes the way people feel about their involvement in research."

As for the LGG Registry, enrollment into OPTIMUM is via the internet or on-site in the United States at Brigham and Women's Hospital in Boston, Massachusetts. Participants who are currently aged 21 years or older and who have undergone two or more surgeries for their glioma (regardless of additional treatment) are eligible and are asked to complete a short online questionnaire as well as provide a blood sample. With participant consent, the OPTIMUM research team will locate and collect available tumor samples from surgery so that they may be genotyped.

To reach the study goal of 500 people enrolled with recurrent LGG, Dr. Claus and the OPTIMUM team are seeking people living with recurrent LGG to participate. People who are already Registry members and who have had additional surgery since time of registration will also be eligible.

Your participation in this effort will bring much needed research to foster better understanding of LGG and the timing and type of more effective treatments for this tumor type. ■

To join the registry or learn more, visit the study website at: <https://lggregistry.wixsite.com/study>, email glioma@yale.edu or scan the following QR code:



Commonly Asked Questions:

Question: If I was initially diagnosed with a grade 2 or 3 glioma but am now diagnosed as a higher grade glioma (3 or 4), am I still eligible for the study?

OPTIMUM Team: Yes. The only requirement is that the initial tumor be grade 2 or 3. Enrolling patients with pathology collected at multiple time-points is very important to the study as it allows us to examine whether genetic mutations in LGG tumors stay the same or change over time. It also allows us to see how treatment (radiation and/or chemotherapy) may be associated with changes in genetic mutations within the tumor. This information may be used to better guide treatment if a tumor recurs.

Question: I was diagnosed as a child with glioma so am I eligible for OPTIMUM or the Registry?

OPTIMUM Team: The focus of the Registry and OPTIMUM is on adult glioma thus people diagnosed with a childhood glioma are not currently eligible.

Question: What if my glioma is recurrent but I have only had one surgery?

OPTIMUM Team: As we are looking to see what changes from the first to second surgery, only people with two or more surgeries are eligible for OPTIMUM. People with LGG and one surgery are still eligible to enroll in the Registry.

Keep up to date...

The International Brain Tumour Alliance maintains a constantly-updated list of major regional, national and international neuro-oncology and cancer conferences and other meetings relevant to brain tumours.

These conferences and meetings include those organised by brain tumour patient organisations, medical societies and others.

Educational webinars and virtual events are also listed on the IBTA website calendar.

If you are organising or are aware of a forthcoming patient/brain tumour advocacy event or a scientific conference, whether it is virtual or in-person, taking place in 2022 or 2023, please let us know by emailing kathy@theibta.org

You can view the IBTA calendar of events here: <https://theibta.org/events-and-conferences/> ■

Walk Around the World for Brain Tumours COVID-style

How the PVW Brain Tumor Foundation in Hong Kong
joined the event in a novel way



Sarah Rigby, General Secretary, PVW Brain Tumor Foundation
Hong Kong

In the fourth year of our existence and frustrated by COVID restrictions in Hong Kong that forbade mass gatherings, the PVW Brain Tumor Foundation decided to join Walk Around the World 2021 in our own special way.

What we did

Starting during Brain Tumour Awareness Week 2021, we encouraged people to plan a hike of any length in groups of four or fewer (to keep within COVID-19 rules at the time in Hong Kong), take a photo and post it on our social media sites, recording the distance walked. To encourage participation and to add an element of fun, we designed and printed off bespoke cooling towels for people to hold up during their walk and include in their photo. You can see that not only were people prepared to be adventurous but they truly enjoyed an excuse to get away from the tensions of the city and enjoy the beautiful countryside that Hong Kong has to offer.

What we learnt

We may not have set any distance records, but we found out that more than a hundred people were eager to join in and focus on what they could do rather than what they couldn't, which surely has to be the spirit of the times. Supporters walked 318 miles but we were more delighted with intangible gains such as raised awareness (of brain tumours and our group) plus the thought that we had



Sarah Rigby is the General Secretary of the Hong Kong based PVW Brain Tumor Foundation (PWBTF)

found more supporters in the community, people who would play their part in future activities. ■



Hong Kong-based PVW Brain Tumor Foundation (PVW BTF) was set up in honour of Pieter Vance Wyckoff (PVW), a talented bass trombone player and member of the Hong Kong Philharmonic Orchestra.

Pieter was diagnosed with a glioblastoma (GBM) in 2018 and the Foundation was launched with a concert on 21st May 2019, shortly after his passing. The Foundation continues with the support of the musicians of the Hong Kong Philharmonic plus other musicians in the region and around the world. This close musical association is reflected in the charity's logo, which features a baton, and our rallying call is: "Play your part!"



Members of the PWBTF Board

Our 2021 PVWBTF Album



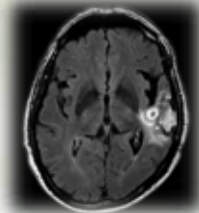
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“SIMO...alla meta 2022”: Memorial Simone Luffarelli - 8th Edition

Marco Luffarelli, President, Asd Chaos Primordiale
Italy

This year we organized the eighth edition of “SIMO ... alla meta”, a charity event in memory of Simone Luffarelli, who died in 2006 at the age of 21 from a brain tumor.

Since 2015, with our friend Valerio Rahim, we have been organizing this day of celebration with our Primordial Chaos Sports Association.

Since the first edition we have been donating an average of € 1,000.00 per year to the IRENE Onlus Association, the Regina Elena Hospital Association, which supports brain tumor patients and their families.

After the “Home Edition” online during the full pandemic in 2020 and the “Workout Edition” in 2021 to keep a safe distance, once again this year due to some organizational challenges with local officials we had to replace the usual SIMO...alla meta” race in the Esquilino district in Rome with a workout in the beautiful Piazza Vittorio Emanuele II.

As usual, we didn’t give up and we reshaped the day, remembering my brother was too important to be able to skip a year.

With the support of the Municipality I of Rome (an area encompassing the centre of the city) and our sports promotion body (ENDAS) we were able to organize yet another



Marco Luffarelli, right (President of Asd Chaos Primordiale) and Valerio Rahim (Vice-President and coach), left

day of celebration in honor of Simone.

In my usual speech, I wanted to reiterate my thanks to those present because they give us the strength to go on and give us an excellent reason to remember Simone with a smile.

Furthermore, I wanted to remind everyone that life is too short to spend it in solitude with the sole desire to excel

in any field, when instead it should be necessary to share the joy of life with as many people as possible, especially with those who do not have the same luck as ours. ■

Below: The 8th Edition of “SIMO...alla meta 2022” was well supported by family and friends of Simone Luffarelli, in his memory

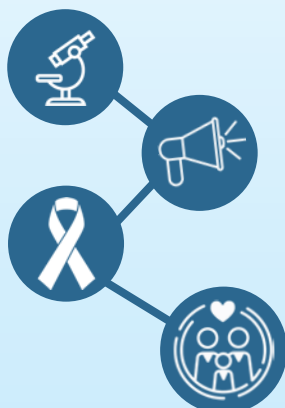




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This artwork was donated by an artist who is the wife of a patient. The chameleon is a symbol of the multiform nature of glioblastoma that changes and becomes resistant to drugs and is different for each person. The flower is a symbol of hope.

Glioblastoma.IT ODV

Glioblastoma.IT ODV is aimed at patients and caregivers with an eye on the panorama of international research and the goal of being of help in the short and medium term by providing updated information on specialized centers for the treatment of glioblastoma and putting in contact patients and caregivers with high-profile professionals. The funds we raise are intended to maintain our services and support patients who wish to try second line therapies through trials but also in the absence of trials or while waiting for the clinical trials begin.

If you are a patient or a caregiver visit our websites

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Raymond A. Wood Foundation Tackles Survivable Brain Tumors That Pose a High Price for Survival

Amy Wood, Executive Director, Raymond A Wood Foundation
United States



It was a regular Thursday morning in May 2015. My then four-year-old son Alex was up and ready for library day, his favorite day of the week in pre-kindergarten. While I was having my coffee and getting awake, something about Alex's left eye caught my attention. It seemed to be off-center, almost crossed inward. We have a history of lazy eye in the family, so I thought maybe I hadn't noticed it before. Nothing else seemed wrong, so off he went to school, and I made an eye doctor appointment.

But as the day progressed, I started getting messages from his teacher. "Have you seen Alex's eye?" she said. "He seems to be having trouble with his balance."

A shocking diagnosis

We went to see Alex's pediatrician that afternoon, and he immediately instructed me to take Alex to the nearest children's hospital, which was three hours away. He simply said it could be a brain tumor or brain cancer. That was so incredibly shocking to hear, and I will never forget that moment.

It was the most harrowing next 24 hours — the drive to the hospital, the first MRI and then the news that Alex had a mass in the middle of his brain causing hydrocephalus. They moved him to the pediatric intensive care unit at the hospital that night, and early the next morning, they took him into surgery.



Amy Wood, Executive Director and Co-Founder of the Raymond A Wood Foundation based in Ocean City, Maryland, USA

The neurosurgeon told my husband, Shawn, and me that it was a benign tumor believed to be a craniopharyngioma and that it was fully removed. Hearing the tumor was benign seemed like a relief, but as the hours and days unfolded after surgery, we soon learned that we had a long road ahead.

As a result of the tumor surgery, Alex developed diabetes insipidus (DI), the absence of the antidiuretic hormone vasopressin due to pituitary damage, which made it challenging to manage his body fluid balance and keep his blood sodium level in a safe range. This kept him in the hospital for six weeks. When we asked how we measure his sodium at home, we were quickly made aware that this is a rare condition and that at-home testing of blood sodium is not available — unlike typical diabetes where you can test glucose.

Alex was also adipsic in that he lost any sense of thirst from hypothalamic damage, so we could not rely on thirst as an indicator of his hydration level. Additionally, he developed panhypopituitarism which is loss of endocrine function, adrenal insufficiency, and hypothalamic obesity (HO) which is excessive weight gain combined with an insatiable hunger.

Challenges for optimal care

After discharge, Alex was getting lab work done up to four times a week where we waited hours for results. His veins were blowing out from constant poking. We were measuring how much he drank and how much he urinated to calculate fluid intake. He had three seizures due to low blood sodium that put us on medical flights to the children's hospital, where it took him days to recover.

I felt strongly that this situation was not sustainable, and we needed a solution. We discovered a hospital-grade handheld blood analyzer that could do full basic metabolic panels at home, with a finger stick producing accurate results in less than five minutes.

There were significant roadblocks to getting the device — the price tag is around US \$12,000 with test cartridges and the fact that it would be used off-label where there was really no prior experience with using it for this purpose. But we sensed it would be a game-changer. With the help of Alex's pediatrician and support from our local community, we raised money and purchased one.

This device was life-changing. We could test Alex's sodium at home and make quick medication and fluid adjustments to keep his sodium in range. Since receiving the device, he has had no sodium-related hospitalizations. It also peeled away one of the most complicated layers of management of his challenging post-tumor treatment. Shawn and I knew there were others like us that may benefit from using this device, so we created the Raymond A. Wood Foundation (RAWF) in 2017 to raise money to purchase and provide these devices to pediatric brain tumor patients with adipsic diabetes insipidus.

We also realized early in this brain tumor journey that there was no U.S. based organization primarily focused on craniopharyngioma. Because of the excellent survival rate in craniopharyngioma, the high cost of survival is often not satisfactorily addressed as a priority. Many survivors face complete loss of endocrine function, neurocognitive impairment, blindness, uncontrollable obesity (hypothalamic obesity), temperature dysregulation and memory issues. Craniopharyngioma in particular affects both children and adults, and is also highly recurrent and characterized as "malignant in place."

The Raymond A Wood Foundation

We began to position the foundation to be the premier patient advocacy organization for survivors of hypothalamic-pituitary brain tumors. In 2020, I left my full-time job as a creative director of a web development agency to become the executive director of the Raymond A. Wood Foundation. We added key opinion leaders to our board and redeveloped our mission to serve adult survivors in addition to children, because we discovered a significant unmet need in ongoing treatment of the comorbidities of these tumors in adults. ➤

Right: The Raymond A. Wood Foundation recently attended the Chan Zuckerberg Initiative, "Rare As One Convening" where 50 rare disease organizations joined to learn and share around advancing treatments. The Raymond A Wood Foundation delegation included (from left to right), Eugenie Hsu, Ph.D, Board Chair; Amy Wood, Executive Director; Nathalie Kayadjanian, Ph.D, Scientific Advisor; and Cassie Kline, MD, Neurooncologist, Children's Hospital of Philadelphia



Raymond A. Wood Foundation founders, Shawn and Amy Wood with son Alex, days after craniopharyngioma surgery



Currently, RAWF's focus is on supporting efforts to develop better treatment outcomes particularly for craniopharyngioma, while finding solutions for the myriad long-term challenges like diabetes insipidus (DI) and hypothalamic obesity (HO), which is characterized by uncontrollable obesity recalcitrant to diet and exercise and can also present with hyperphagia, or an insatiable hunger. RAWF recently hosted a patient listening session with the US Food and Drug Administration (FDA) on HO, and we are working closely with pharmaceutical companies and key HO researchers to find an effective treatment. We also host a yearly family conference in collaboration with Children's Hospital of Philadelphia (CHOP) where we offer the opportunity for families to engage with physicians and researchers while also connecting with each other on these topics.

Making a real difference for craniopharyngioma patients

In 2020, we initiated the development of a sodium meter, akin to a glucometer, that could be FDA-approved, insurance-covered and more user-friendly by using a small blood volume. This project is in phase one development in collaboration with Drs. Shana McCormack and Khushbu Patel of CHOP and Giner Labs, whose initial development work has been funded by an NIH SBIR[MOU2] grant.

Recently, we were named a grantee of the Chan Zuckerberg Initiative's (CZI) "Rare As One Network". Under that three-year grant, we are developing a research roadmap and building a patient-led collaborative research network with a focus on reaching underserved craniopharyngioma patient populations.

Fortunately, my son Alex never had a recurrence, but this tumor takes up a big part of our day-to-day lives, impacting everything from his ability to learn and make social connections, to his physical capabilities, sleep and wake cycles, and even his speech articulation. I have made it my life's work to increase awareness around the need for more patient-centered, future-focused treatments to mitigate these lifelong effects. Survival is a true blessing, but the price is steep. I believe we can make a difference in that cost for future craniopharyngioma survivors. ■



Dr. Craig Alter (left), neuroendocrinologist at Children's Hospital of Philadelphia and Amy Wood (right), co-presented on diabetes insipidus management at the inaugural Pituitary Brain Tumor Family Conference

For more information about the work of the Raymond A. Wood Foundation, visit www.rawoodfoundation.org

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

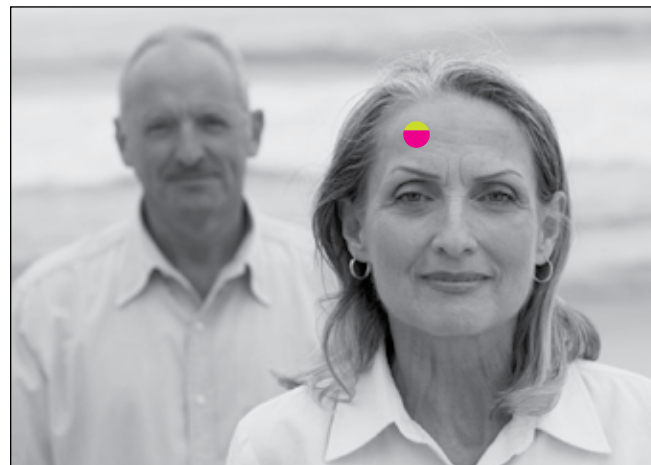
The Brain Tumour Patients' Charter of Rights has worldwide relevance and sets out an aspirational framework for improving healthcare systems and communications. Read the Charter at <https://theibta.org/charter/>

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The Norwegian Brain Tumour Association

The Association was established in 2009 and is an independent, national organisation for people who have or have had brain tumours, their families and other interested parties.

Please see www.hjernesvulst.no

If you are interested to sign in as a member or learn more about us, please contact us at post@hjernesvulst.no



Hjernesvulstforeningen

braintumor.nl sterkenpositief.nl



We are proud of all researchers who want to make a difference for brain tumor patients!

STERK en positief

GOED DOEL



<http://gfme.free.fr>

GFME 20 years

GFME, Glioblastoma Foundation Michele Esnault, established in 2001 is a French-based (Marseille), patient-oriented, a support group involved in brain tumors. GFME translate and published 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 Paris, Brain Tumor Association For Research to raise funds. GFME is a website <https://gfme.fr>, a quarterly magazine, a phone assistance (33) 04.91.64.55.86, and a mailing-list mailing@gfme.fr. The group includes 700 patients, care givers, friends and family members around the globe. For more details gfme@free.fr



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- Conference dinner on the 'Ferry across the Mersey'

REGISTRATION

Visit our Conference website for more details and to register:

www.delegate-reg.co.uk/pfs2022

www.posteriorfossasociety.org



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OUR OBJECTIVES -In the era of genomic medicine-
Improve medical care system for rare cancer patients.

Develop better treatments (surgery, drug therapy, radiation therapy, immunotherapy, nuclear medicine, etc.)

Accelerate basic research, translational research, and clinical trials to find a cure.

Create a society more adapted to rare cancer patients and their caregivers and provide them with relevant information and a higher quality of life.

OUR NETWORK IN JAPAN

Cure Sarcoma
DIPG Symposium Organizing Committee
Ewing Sarcoma Patient Family Group
Family support group for Retinoblastoma (Sukusuku)
FUTATSUBA - Thymoma/Thymic Carcinoma Patient Support Group
GISTERS (NPO for GIST patients)
Head and neck cancer Patients and their families Association "Nicotto"
Japan Association Mesothelioma and Asbestos Related Disease Victims and their Families
Japan Brain Tumor Alliance (JBTA)
Japan Sarcoma Patients Network "TANPOPO"
Life Message from the Late Takashi Yamamoto, Thymic Carcinoma Patient
Lisianthus support group for Children Diseases
Melanoma Patients Association - Over The Rainbow
Mesothelioma Support Caravans
Neuro-Endocrine Tumor Patients Association (PanCAN Japan)
Neuroblastoma japan family Network
Pediatric Brain Tumor Network of Japan (PBTN)
PMP patients' Network of Japan
Rhabdomyosarcoma Family Network
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CBTRUS



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SURVIVAL
LIFETIME RISK
PREVALENCE
MORTALITY



The ZBTA Continues to :

- Advocate for improvement in the access to treatment, early diagnosis and provision of quality care for brain tumour patients and survivors in Zimbabwe.
- Co-ordinate the efforts of all stake-holders in reviewing, as well as setting policy frame works and standards in provision of better services.
- To provide hope and deliver better treatment outcomes for patients such as :
 - Well equipped theatres
 - Advanced brain tumour treatment machinery
 - Brain tumour research centres
 - Access to affordable diagnostic imaging services
 - Running campaigns to have all health personnel in satellite clinics sensitized on signs and symptoms of brain tumours

Achieving Through Hope & Strength

Email : zbtainfo@gmail.com
<https://m.facebook.com/Zimbabwe-Brain-Tumour-Association>

SWEDISH
BRAIN TUMOR
ASSOCIATION



We enhance quality of life – supporting brain tumour patients and care givers through support groups, events and lectures where we share with each other and learn about the disease.

We advocate – spreading information that may be helpful to anyone who needs facts about the disease and the patient and caregiver situation.


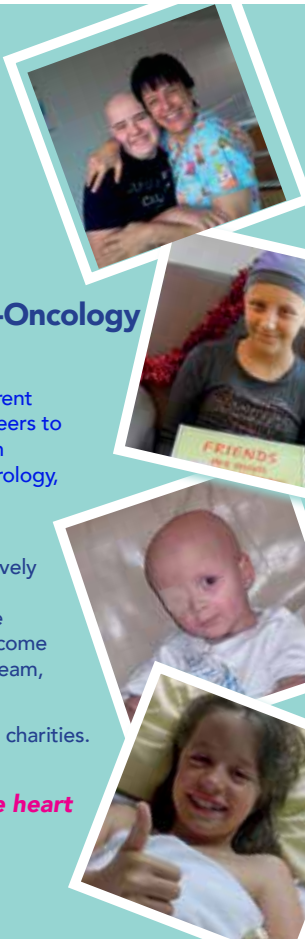
We promote more equal care – contributing to keeping the national care programs constantly updated so that the best care and treatment methods are available to all brain tumor patients, regardless of their place of residence.

We follow the research internationally – in constant dialogue with healthcare professionals, researchers, healthcare policy and other decision makers.

For more information visit us on our website:

www.hjarntumorföreningen.se

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Astro Brain Tumour Fund is working hard to end the anguish for those living with this devastating form of cancer by funding research in the UK and providing a Facebook support group for patients and carers.

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 Mary on **01485 52 52 79**
treasurer@astrofund.org.uk
 Linda on **02084 05 88 53**
lindatrustee@astrofund.org.uk
 or browse our website at www.astrofund.org.uk



Cyprus Brain Tumour Association

- Offers Support and encouragement to brain tumour patients and their families
- Aims to achieve recognition of the specific challenges brain tumour patients and their carers face in dealing with the disease
- Gives information for brain tumour patients to assist making treatment decisions
- Supports research for the development of more

Tel.: 0035799616113
 Email: cybraintumour@hotmail.com / sotosol@cytanet.com.cy

4B Agiou Damianou Street • 2054, Archangelos • Nicosia • Cyprus
 Facebook: **Cyprus Brain Tumour Association**



Bringing together a community of brain tumour patients, caregivers and medical professionals. BTSS is working to:

- Achieve recognition of the specific challenges brain tumour patients and their carers face
- Help reintegrate survivors back into work and education
- Establish real investment in neuropsychologists and more effective long-term treatment for patients.
- Legislate for mandatory data collection in both public and private hospitals in Singapore of both malignant and non-malignant brain tumours.

www.braintumoursociety.org.sg
enquiry@braintumoursociety.org.sg

Brain Tumour Support Group and Awareness Foundation India celebrates Brain Tumour Awareness Week 2021

Dr Nitin Garg, MBBS, M.S., M.CH (Neurosurgery), Bansal Hospital, Bhopal, India



The International Brain Tumour Awareness Week (IBTAW) is the time of year when various activities are conducted to raise awareness about this medical condition. In 2021, there was active participation and involvement with COVID-19 under control.

The second half of this awareness week fell during "Diwali", an important festival in India. Hence, we conducted most of our activities in the first half of the week to ensure appropriate participation.

At last – a physical meeting for brain tumour patients and caregivers

This was the first physical meeting in over 18 months since the start of the COVID-19 outbreak, although throughout the COVID pandemic virtual meetings continued. This was well attended by brain tumour patients and caregivers. They were very enthusiastic in their participation. The participants were well acquainted with each other through the virtual online patient support group meetings which were held every month. They were very happy and pleased to meet each other face-to-face.

At our physical meeting, there were talks, dance performances and songs sung during our two hour programme. Those who could not attend shared their



Dr Nitin Garg

messages and performances through videos. Ms Komal Syed from the Brain Tumour Foundation of Pakistan also participated in this meeting and sent her video message. With language not being

a barrier, there was instant connection amongst participants, on listening to her message. Everyone was very pleased with the energy levels and the positivity in the air.

This meeting was also attended by other medical specialists and paramedical staff. The entire meeting was telecast live on "Facebook Live".

Brain tumour awareness-raising on the radio

The local Bhopal FM radio channel conducted interviews of patients, caregivers and counsellors and telecast these talks daily for two hours from 31st October to 3rd November 2021. Brain tumour patients and caregivers highlighted the importance of being part of a support group and how it helped them during the critical moments on their brain tumour journeys. ➤



Khusboo Lohan, Neuro-Rehabilitation Psychologist, BTSG Awareness Foundation



Divya Kispotta, Medical Social Worker, BTSG Awareness Foundation



The participants at this in-person awareness raising meeting organized by the Brain Tumour Support Group and Awareness Foundation India were already well acquainted with each other through virtual online patient support group meetings but were very happy to finally meet each other face-to-face

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK
30th October - 6th November 2021

TUMOUR TREATMENT FACTS

- 01** 120 different types of Brain Tumour
- 02** Surgery required for majority
- 03** Radiotherapy & Chemotherapy required for Malignant tumors
- 04** "Time is Brain" timely treatment is effective, avoid delays in treatment
- 05** Surgery, Radiotherapy & Chemotherapy is safe with recent advances

www.btsgfoundation.in

An awareness-raising poster shown in Indian hospitals during International Brain Tumour Awareness Week 2021

Television channels also played a role in raising awareness

There were four programmes of 30 minutes' duration each conducted on Doordarshan and Bansal News channels under their Social Awareness Programmes. Each of these programmes had an interactive Q&A discussion between a neurosurgeon, a patient, a counsellor and a caregiver. There was also a live question session from viewers watching the Bansal News programme. Various aspects about brain tumour treatments and misconceptions, the importance of psycho-social support and patient support groups were highlighted in these programmes.

Social media spreads the word


The physical brain tumour meeting and radio channel interviews were also telecast on Facebook. In addition, websites and Twitter were used to highlight various aspects related to brain tumours.

In-hospital awareness activities

Various printouts and standees were placed in hospitals to raise awareness amongst patients, caregivers and medical personnel about the various treatment-related aspects of brain tumours.

Participation in "Brilliance!" - A Virtual Online Art Exhibition

The Brain Tumour Support Group and



"Caring for Care Givers"

BTSG
Awareness Foundation India
Information, Support, Compassion

Brain Tumour Foundation
... of India ...

IBTA
INTERNATIONAL
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ALLIANCE

ISNO
Indian Society of
Neuro-Oncology
www.isno.in

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

30th October - 6th November 2021

When you get the Brain Tumor diagnosis
You learn 2 things...

- You are **Stronger** then you Imagined
- You are **Loved** more than you Knew



Awareness Can Only Make Cure Possible
Get in touch for support & information www.btsgfoundation.in

One of the posters exhibited in hospitals to raise awareness about brain tumours



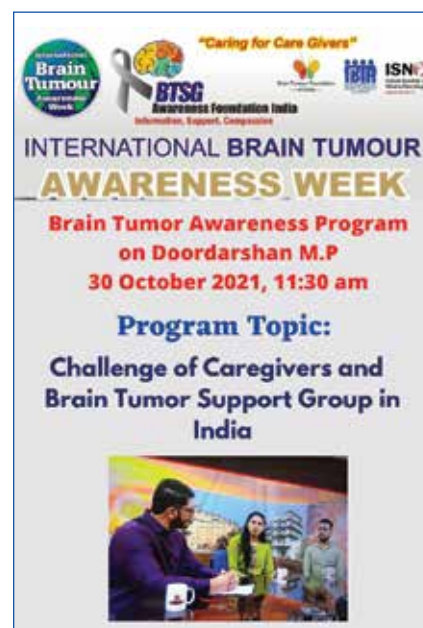
Jaya Pal, a brain tumour survivor and one of the speakers sharing her story at the in-person meeting of the Brain Tumour Support Group and Awareness Foundation India

Awareness Foundation India motivated and helped patients to submit their original artwork to an online exhibition organized by the International Brain Tumour Alliance (IBTA) for brain tumour patients, their caregivers and medical professionals. (To see the entries from India in the 2021 "Brilliance!" exhibition see pages 29 to 70 of this edition of *Brain Tumour* magazine.)

In conclusion...

The 2021 awareness week had a good and enthusiastic participation from patients and their caregivers in India. With the COVID-19 outbreak under control, it was a very positive physical meeting for participants. ■

For more information about the Brain Tumour Support Group and Awareness Foundation India, please visit <https://btsgfoundation.in/>



"Caring for Care Givers"

BTSG
Awareness Foundation India
Information, Support, Compassion


IBTA
INTERNATIONAL
BRAIN TUMOUR
ALLIANCE

ISNO
Indian Society of
Neuro-Oncology
www.isno.in

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

**Brain Tumor Awareness Program
on Doordarshan M.P
30 October 2021, 11:30 am**

Program Topic:
**Challenge of Caregivers and
Brain Tumor Support Group in
India**



Awareness-raising about the challenges of brain tumours got air time on radio and television programmes throughout the International Brain Tumour Awareness Week 2021

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EURACAN specialists also invest in joint research activities, organise trainings for healthcare professionals and work together on Clinical Practice Guidelines. www.euracan.eu

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This project is cofunded by the European Union

As of April 2022, EURACAN includes 106 centres across 25 EU member States with high expertise in rare adult solid cancers



A BRAIN TUMOUR AND ME

A NEW
PODCAST
SERIES FROM



To mark the 2021 International Brain Tumour Awareness Week, the IBTA launched its new podcast series, "A Brain Tumour and Me - a journey of inspiration, personal stories and hope".

In this series, we meet some of those working in the field of neuro-oncology, the people who support patients and their families and those who have been told they have a brain tumour. We learn how brain tumours have affected all of these people, often in surprising ways.

Dr Stuart Farrimond



Dr Stuart Farrimond (right) speaks with the IBTA's podcast producer and interviewer Graham Seaman (left) about his brain tumour diagnosis

The series began with an episode about Dr Stuart Farrimond from Trowbridge in the United Kingdom who spoke about his experiences of living with a brain tumour, how it offered unexpected opportunities to do things he had never contemplated before diagnosis and what having the support of family and friends truly means. As a science communicator, Dr Stu also shares his personal hopes for the future of neuroscience and neurosurgery.

Dr Stu was diagnosed with a malignant brain tumour in 2008 after which he left active medical practice. He retrained

as a further education health sciences lecturer and as he says: "I discovered a passion for science communication – something I now feel fortunate to do fulltime."

Dr Stu uses his experience in medicine and science alongside his powerful personal story as a cancer survivor to present and write about science and health. He makes regular appearances on radio, TV and at public events. He has been the food scientist for the BBC's Inside the Factory and is the author of several international best-selling books.

Dr Alfredo Quiñones-Hinojosa



Dr Alfredo Quiñones-Hinojosa says in the IBTA podcast episode that: "Hope is the only emotion that allows us to keep going..."

The second episode of "A Brain Tumour and Me" features American neurosurgeon, author and researcher Dr Alfredo Quiñones-Hinojosa who speaks about his remarkable journey from the humblest of beginnings in Mexicali, Mexico to become a world-renowned neurosurgeon and neuroscientist. Dr Alfredo Quiñones-Hinojosa is the William J and Charles H Mayo Professor and Chair of Neurologic Surgery and runs a basic science research lab at the Mayo Clinic in Jacksonville, Florida, United States.

His research work focuses on brain tumours and cell migration, healthcare disparities and clinical outcomes for neurosurgical patients.

In this IBTA podcast episode, Dr Alfredo Quiñones-Hinojosa reveals the dramatic, life-changing accident he had at age 21 and how his brain tumour patients have inspired his work. ➔

Claire Karekezi



The third episode of “A Brain Tumour and Me” features Rwanda’s first and only female neurosurgeon, Dr Claire Karekezi. Dr Karekezi is a consultant neurosurgeon based at the Rwanda Military Hospital in Kigali, the capital of Rwanda. Dr Karekezi has a special interest in neuro-oncology, skull base surgery and endoscopic endonasal surgery.

In this IBTA podcast episode, Dr Karekezi talks about her amazing journey to become a neurosurgeon, why she is so inspired by her brain tumour patients and how she hopes to help improve the quality of care for brain tumour patients in Rwanda.

Claire tells the IBTA’s podcast producer and interviewer Graham Seaman: “I think everything I do is about hope...Every time I wake up and I go to work, sometimes I don’t have all the answers, but...I’m ready to help someone...I remember all my tumour patients...I can put a name and a face to everyone and I know what I did for everyone. I know how everyone is doing...this is the kind of connection you build with them.”

Dr Claire Karekezi, Rwanda’s first and only female neurosurgeon

Christine Hals



Christine Hals helped to care for her stepfather who was diagnosed with a glioblastoma

The fourth episode of “A Brain Tumour and Me” sees Norwegian-Swedish singer/composer Christine Hals speaking with IBTA podcast producer Graham Seaman about her experience of being a caregiver to her stepfather who was diagnosed with a glioblastoma. Christine talks about how her love of music, performing in Disney’s Frozen and Frozen 2 movies and scoring her very first feature film have helped her cope emotionally with loss, while also discovering hope in the darkest of times.

Christine has composed music for documentaries, features and short movies, some of which have won awards. As a young composer, Christine was head-hunted by Disney Studios because they needed Norwegian lyrics and vocals for their film Frozen, and Christine had the perfect artist background for this. As a young girl, she herded goats using a high-pitched singing style known as “kulning”, a sample of which listeners can hear on the IBTA podcast.

As a former caregiver to her stepfather, Christine said: “I think that it’s important to take care of yourself. Also, once someone has a...terminal illness, all you want to think about is trying to save them, and you kind of forget everything around you. And I think it’s also important to ask for help because you cannot handle all of this on your own. Make sure that you take care of yourself and make sure that you get help when you can... And also just remember to live, remember to enjoy, remember to actually spend as much time as possible with the people you love.”

Miranda Shipman



Being told she had a very rare type of brain tumour - an epidermoid tumour - at the age of just 27 is something Miranda Shipman from North Carolina in the United States certainly wasn’t expecting. But it was an event that reshaped her life in so many ways.

In the fifth episode of the IBTA’s podcast, “A Brain Tumour and Me”, Miranda talks to our reporter Graham Seaman about how she coped with the news of her first diagnosis and the surgery that saved her life. Miranda describes what happened when she discovered that the tumour had later returned and how she now faces the future.

Miranda Shipman was diagnosed with a very rare epidermoid brain tumour at age 27

Denise Bebenek



Denise Bebenek – a mother on a big mission!

Denise Bebenek from Toronto in Canada lost her five-year-old daughter Meagan to an inoperable, malignant brain tumour. In the sixth episode of the IBTA podcast, “A Brain Tumour and Me”, Denise explains how out of this unimaginable tragedy

Meagan’s Hug was established as a programme to harness the power of community, togetherness, awareness raising and hope.

Denise said: “How sad if we didn’t have hope in our day-to-day lives. You know, no one said life would be easy. We do the best we can with our life circumstances. And I always encourage families to just

take things one day at a time, one moment at a time. And hang on to each other because there’s a lot to be said about a family, a community...You’re not alone.”

As well as creating awareness about paediatric brain tumour research and raising vital funds to support important research projects, Meagan’s Hug also supports families. ■



“A Brain Tumour and Me”

is currently available via Apple Podcasts, Google Podcasts, Spotify, Castbox and Anchor. The podcast can also be accessed on the IBTA’s website at <https://theibta.org/category/podcast/>

“A Brain Tumour and Me - a journey of inspiration, personal stories and hope” has been produced by Graham Seaman Media for the International Brain Tumour Alliance (IBTA).



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5 – 7 July 2023

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The Danish Association for brain tumor patients and relatives



HJERNETUMORFORENINGEN
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- share valuable experience between healthcare workers and patients
- increase public awareness of this patient group.

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Awareness of Brain Tumours
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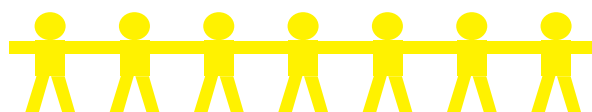


**An association for Brain Tumour
Patients in the West of France**

We seek to


- raise awareness on brain tumours
- bring moral and/or financial assistance to brain tumour patients and their relatives
- help funding innovative research programmes

« All hands on deck to defeat brain tumours ! »



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- We provide a safe place to share our experiences and lessons learned.
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John Paul II



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**TOGETHER
WE ARE GOLDSTRONG**

Rainbows and Smiles is a childhood cancer foundation based in South Africa. Our mission is to provide, emotional, social and financial support to underprivileged families and caregivers of children diagnosed with cancer.

An average of 800 – 1000 children are newly diagnosed annually in South Africa. Rainbows and Smiles encourages childhood cancer advocacy with a special interest in brain tumours. We strive to educate people, with the goal of promoting early detection. Our principles include hope, smiles and relief.

Rainbows and Smiles promotes **GOLD RIBBON AWARENESS** to educate people, as knowing the early warning signs could save the life of a child with cancer.

We would like to take this opportunity to thank our family of supporters and donors. Without **YOU** none of this would be possible. Over the past 10 years plus, our foundation has flourished and we have been able to deliver a mammoth amount of kindness.

Thank you for your beautiful hearts from our team:
Bonita Suckling, Nadia Lewis, Debbie Riggien, Denise Towell, Gerrida Rorich, Debbie Blake, Catherine Kloppe, Catherine Drysdale, Courtenay Fisher, Barbara Grobbelaar, Mandi Higgins, and Donovan Gaddin.


"Let's make today the funnest day ever"
Jed Brady Thomas-Suckling

For further information please do not hesitate to contact:

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PASNO Pakistan Society of Neuro-Oncology

www.pasno.org

PASNO aims to improve the care and treatment of brain tumor patients in Pakistan and in the region by enhancing public awareness of neuro-oncology, organizing academic activities for professionals, facilitating multi-disciplinary collaboration to stimulate locally relevant research, and networking with neuro-oncologists around the world. Our vision is to nurture and produce leaders in global neuro-oncology.

Pasno membership is open to neurologists, neurosurgeons, medical and radiation oncologists, radiologists, nurses, students, and any healthcare provider interested in neuro-oncology



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

The IBTA brings together experience and expertise from all over the world with the aim of enhancing well-being and quality of life for brain tumour patients and their families.


By working together, we identify collaborative actions across the international community and work towards our vision of a world free from the fear of brain tumours.

www.theibta.org


PBTN Pediatric Brain Tumor Network **JAPAN**

We are working together to improve the treatments and their quality of life of the children with brain tumors in Japan.

- Child Brain Stem Glioma Network
- Child Brain Tumor Parents Support Group
- *cranio park* for Craniopharyngioma patients and families
- DIPG Symposium Organizing Committee
- Ependymoma Parent's Community
- Japan Brain Tumor Alliance
- Pediatric Brain Tumor Support Group in Kinki Area "Miracle Brain"
- Rainbow Colored Train
- The family support group for the Pediatric Brain Tumor patients


 **ISPNO Family Day**
ISPNO2020 Family Day has been postponed since last year, but will be held online on October 30th at 2:00 p.m. (Japan time/with simultaneous translation)

For more information about ISPNO2020 Family Day, please visit this website. pbtnjapan.com/en/



The American Brain Tumor Association is a trusted resource for brain tumor **patients, caregivers and health care professionals** around the world. From a wide range of publications to webinars and educational programs, the ABTA provides information on all tumor types, for all age groups and empowers patients and families by helping them better understand the diagnosis.

LEARN MORE AT
abta.org



Hong Kong, Shanghai and Macao Braintrekkers Walk Around the World for Brain Tumours

In October 2021, Hong Kong's Braintrekkers welcomed the addition of Shanghai Braintrekkers and Macao Braintrekkers to do a massive Walk Around the World for Brain Tumours.


Hong Kong Braintrekkers let the IBTA know that they walked 3513 kms, Shanghai Braintrekkers walked 960 kms and Macao Braintrekkers walked 618 kms. Kilometres were also collected from Braintrekkers in other regions. An amazing total of 5,185 kms was achieved, breaking all previous records.

The organisers of Braintrekking 2021 said: "We hope, through this annual event and the amazing mileage achieved, greater numbers of people in the world will come to learn more about brain tumours and join hands in the battle against this neurological disease. On this side of the globe, we will continue to put our best efforts into optimising medical treatment for brain tumour patients and providing essential support for carers and families. We're also looking forward to Braintrekking 2022!" ■

Memories of walking around the world for brain tumours - Hong Kong, Shanghai and Macao style!








Collaborative Ependymoma Research Network

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cern-foundation.org  National Brain Tumor Society



Brain Tumour Alliance Australia Inc.
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- Monthly e-news service.
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- Patient forums with international experts.
- Representing the patient in government and policy making.
- Educational grants for allied health professionals.

btaa.org.au
Support: **1800 857 221**

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www.gemeinsamgegenglioblastom.eu




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 **Bambino Gesù**
An international research team has recently discovered a new therapy to inhibit the growth of diffuse midline gliomas, very aggressive primary CNS tumours still without a curative care

AiPBAND: An Integrated Platform for Developing Brain Cancer Diagnostic Techniques

Erik Samuelsson, Early Stage Researcher, AiPBAND,
Stockholm University, Sweden



An Integrated Platform for Developing Brain Cancer Diagnostic Techniques (AiPBAND) is a research program training a new generation of entrepreneurial and innovative early-stage researchers (ESRs) to develop new biosensing techniques and diagnostic systems for the early diagnosis of brain tumors using molecular biomarkers in the blood. The project is approaching completion, and we are pleased to bring you an update from the ESRs to review what they have accomplished during this project.

AiPBAND has focused on gliomas, a category of devastating and progressive brain tumors affecting around 25,000 people each year in Europe and responsible for the majority of deaths from primary brain tumors. Despite extensive study in the field, to date there are no clinically validated biomarkers for reliable diagnosis and grading of glioma.

The research objective of AiPBAND is to work to solve this problem, using state-of-the-art technologies to identify novel biomarkers from patients with gliomas, design multiplex biosensors for the detection of these biomarkers, to evaluate these systems through proof-of-concept through preclinical studies, and to study how biomarkers correlate to tumor development.

Each student participating in the AiPBAND initiative has taken on an individual research project, and worked to set its aim and objectives toward the common goal of improving the diagnostic prospects and our understanding of GBM.

Meet the AiPBAND Early Stage Researchers

In the following section, we'll have the opportunity to hear from some of the AiPBAND students about their individual projects.



Mina Safarzadeh: Mina is from Iran and was hosted as an ESR at the University of Plymouth in the UK. Her project has been to develop graphene-based biosensors for the detection of methylated DNA. Toward that end, she has developed two biosensors with wide dynamic ranges and high selectivity. Both of these sensors can be tailor-made to detect other methylated DNA sequences. One of these biosensors was shown to detect a single strand methylated DNA in the femtomolar range (having a concentration of 10-15 moles per litre) and the other detected double strand methylated DNA in the picomolar range (having a concentration of one picomole per litre). Preclinical studies were conducted in plasma for one of these sensors and the sensitivity was shown to be high.



Vanessa Jungbluth: Vanessa is originally from Germany and was hosted as an ESR and PhD Student by the University of Catania in Sicily, Italy. Since her early career, she has been working on improving and simplifying medical diagnosis for patients. During her previous work for Philips Handheld Diagnostics and the Austrian Institute of Technology, she worked on different methods for a fast and reliable diagnosis of various medical conditions such as heart attacks, influenza infections or colon cancer. During her PhD, Vanessa worked to improve the diagnosis of brain tumors. Usually, such tumors are detected using an invasive biopsy. She showed that it is also possible to diagnose brain tumors by using a biosensor to detect little disease-specific molecules (called microRNAs) circulating in the blood stream of patients. Such an analytical device requires only a small blood sample and thus makes the diagnostic procedure easier, faster and less harmful to the patient. Today Vanessa is working for a company that develops a novel instrument used for various diagnostics tests, still following her goal to make medical diagnosis easier. ➤



Yagmur Yildizhan: Yagmur received her B.Sc. degree in physics at Bilkent University (Ankara, Turkey) in 2016 and her M.Sc. degree in mechatronics engineering (an interdisciplinary branch of engineering that focuses on the integration of mechanical, electronic and electrical engineering systems) at Sabanci University (Istanbul, Turkey) in 2018 where she conducted her research on dielectrophoretic characterization, a technique utilizing electric fields to exert forces on cells to induce changes for optical measurements, and separation of cells. Currently, she continues her research in the biosensors group at KU Leuven in Belgium (headed by Professor Jeroen Lammertyn) as a Marie Curie fellow within the framework of the Horizon 2020 ITN project AiPBAND. Yagmur's research focuses on developing fiber optic surface plasmon resonance, a precise method for measuring the attachment of biomarkers to receptors attached to a metal surface by measuring the changes in light reflected from the surface, and digital enzyme-linked immunosorbent assay (ELISA) technology platforms, single molecule counting method based on the concentration of enzymatic reaction products from the target biomarker into miniscule droplets, for ultrasensitive detection of blood-based tumor biomarkers, particularly extracellular vesicles.



Meenu Selvaraj: Meenu is from India and received her Bachelor of Engineering Degree in Electronics and Communication in 2013 from Coimbatore Institute of Engineering and Technology (Coimbatore, India). When Meenu discovered her interest in the field of electronics, she started her Master's Degree in nanoelectronic systems at Technical University of Dresden (Germany) and obtained her Master's of Science Degree in 2017 from TU Dresden (Germany). She found her passion in the application of bioelectronics and organic electronics, and joined Scriba Nanotechnologie (Bologna, Italy) where she started working in the Scriba's R&D team from February 2018 in the framework of the Marie Skłodowska-Curie Action "iSwitch". In September 2018, Meenu started her PhD at the University of Catania, Sicily, Italy (Department of Chemical Sciences) in collaboration with Scriba Nanotechnologie srl under the Marie Skłodowska Curie Action AiPBAND in which she was involved as an Early Stage Researcher. Meenu's PhD project was based on the development of "Organic Electronic Transistors and Microfluidics for Brain Cancer Biomarker Sensing".



Ana Belén Díaz Méndez: Ana Belén Díaz Méndez, from Spain, is studying for her PhD in Translational Biomedicine at the University of Catania in Sicily, Italy. She is undertaking her AiPBAND project at the Oncogenomic and Epigenetic Unit, Regina Elena National Cancer Institute (Rome, Italy) under the supervision of Dr. Maria Giulia Rizzo. Ana's research is focused on the identification of circulating microRNAs (miRNA) as novel non-invasive diagnostic/prognostic biomarkers in glioma. Using genome-wide analyses, she has identified a three-miRNA signature differentially expressed in serum of glioma patients with different IDH mutation status and correlated both with patients' overall survival (OS) and progression free survival (PFS). Of note, this miRNA signature is also significantly downregulated in glioma patients compared to healthy controls, further revealing its diagnostic and prognostic value as a biomarker (Patent IT102021000005357). Ana is now studying the impact of the three-miRNA signature on glioma biology.



C.C. (Cristian) Ruiz Moreno: Cristian Ruiz-Moreno is from Colombia, South America and is based at the Prinses Máxima Centrum in Utrecht, the Netherlands, under the supervision of Prof. Dr. Henk Stunnenberg. Cristian has been employing state-of-the-art genomic technologies to study highly aggressive brain malignancies in adults and children. His focus is to study cancer heterogeneity and the interplay and influence of the surrounding non-neoplastic cells, known as the tumor microenvironment (TME), to better understand the underlying mechanisms contributing

to tumors' development, progression, and resistance. Looking at every cell individually and its location in space, Cristian aims to characterize the different cell states, cell interactions, and regulatory pathways that influence tumor pathobiology and response to therapy. To date, in this project, Cristian has generated transcriptomic profiles of tumor and non-tumor cells and charted their spatial organization. By integrating both single-cell information and the spatial distribution, characteristic cancer 'niches' and cellular crosstalk between malignant and immune cells that might have implications in developing successful therapeutic strategies for patients affected by this type of disease have been uncovered.



Raquel Oliveira Fonseca: Raquel, from Portugal, is finishing her PhD at University College London (UCL), in the United Kingdom. Since the World Health Organization (WHO) published the new classification for CNS cancers in 2016 (revised again in 2021), which combines a histology and biomarker approach, the urge for new mouse models of glioma was immediate. Raquel's project aimed to establish a new mouse model for IDH-mutant astrocytoma, which can be used for discovery and validation of new candidate biomarkers and therapeutic targets. The model uses genome engineering techniques, such as CRISPR/Cas9 and Cre recombinase to induce mutations that match the genetic profile described in human patients, generating tumors in 30-60 days that closely resemble human counterparts, which constitutes a powerful tool for downstream studies. As she is wrapping up her PhD project, Raquel will look for new opportunities in the pharmaceutical and biotech industries.



Erik Samuelsson: Erik is from the United States and is currently pursuing a PhD at Stockholm University, Sweden, in biochemistry. He was recruited to join AiPBAND after completing a Bachelor of Science in biomedical engineering at Boston University, United States, and a Master's in molecular bioengineering from TU Dresden (Germany). Erik has been using spatial transcriptomics, a technique used to visualize gene expression in human tissue, to profile the cellular architecture of human glioblastoma (GBM) and diffuse midline gliomas (DMG). The work so far has revealed the degree of similarity and differences between patients, as well as the trends of cancer cells associating with non-cancerous cells, and how brain tumors interact with the healthy brain to drive progression. He is also applying his knowledge in tumor architecture to the development of human brain cancer organoid models, with the aim of recapitulating individual features of cancer in these models. The ultimate goal is to develop a human cell-based platform for improved drug testing in GBM.



Birbal Prasad: Birbal is originally from India and was hosted as an AiPBAND ESR and PhD student by the University of Plymouth and Teesside University in the United Kingdom. Previously, Birbal obtained a BS and MS in mathematics from the Indian Institute of Science, Education and Research in Pune, India. During his PhD and as an ESR, Birbal worked on the application and development of statistical and machine learning methods for integrated analysis of genomic data for new biomarker knowledge in glioblastoma. The research work led to the establishment of new statistical and deep learning frameworks and identification of potential biomarker candidates for glioblastoma which necessitate future experimental validation in independent studies. Since February 2022, Birbal has been working at the University of Oxford, UK, continuing his research into improved methods for integrated analysis of omics data for new biological knowledge.



Aira Ong: Aira Patrice R. Ong is a Marie Curie Early Stage Researcher (ESR) and a PhD candidate in the Plymouth Business School, UK. Aira graduated cum laude from De La Salle University (Manila, Philippines) within the BS/MS Honours Program of Manufacturing Engineering as a scholar in 2017. She was also the lead researcher of the AGAPAY Project, which built up her experience on managing biomedical innovations towards their commercialisation. As the AiPBAND Project ESR, her research aim is to develop business models incorporating various stakeholder perspectives across the value chain from technology researchers to healthcare professionals. She has done secondments and collected data where key factors of

innovative business model development in healthcare decision-making have been explored and prioritised. Her research interests include the biomedical devices value chain, business models in healthcare, sustainable value networks and innovation management. Aira is, and has always been, passionate in promoting innovations towards a healthier world.



Ahmed Abdelrahman Ali: Ahmed is a pharmacist from Sudan. His role in the

AiPBAND project is to find the best design for clinical trials to evaluate diagnostic tests for brain cancer, where he has also tested how we can use microRNAs in the blood to identify a class of brain tumors. This test will give us the chance to gather information about the disease without the need for invasive biopsy procedures to get a sample from the tumor and study it in the lab. He is in the final phase of his project, where he has generated promising results regarding the use of microRNAs in brain cancer diagnosis. Ahmed has also collaborated with Catania University in Sicily (Italy) to evaluate a novel platform to detect microRNAs in blood samples, and will compare the sensitivity of the new platform to the quantitative polymerase chain reaction (qPCR), the current standard for microRNAs detection. ■

AiPBAND has received funding from the European Union's Horizon 2020 Research and Innovation program under the Marie Skłodowska-Curie grant number 764281.

For more information on the partners, ESRs and publications of AiPBAND, please visit www.aipband.itn.eu.

For further information about the work of AiPBAND and its participants, please contact Erik Samuelsson at erik.samuelsson@scilifelab.se

Please join us in 2022!

Raise awareness of the challenges of brain tumours and plan an event for **International Brain Tumour Awareness Week 2022 (29 October - 5 November)**

New Addition - Bengaluru Chapter



BTSG
Awareness Foundation India
Information, Support, Compassion
(Brain Tumor Support Group and Awareness Foundation)
www.btsgfoundation.in

Objectives:

- To bring together Brain Tumor Community
- To provide information, guidance, counselling
- Psycho-social support for patients and care givers
- Self-help groups for patients and care givers

We Can Help You By:

- Providing Patient information and Care-Giver brochures.
- Setting up Peer Support Group at your Centre
- Training Psychologists and Counsellors

Who can associate with us?


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Clinicians - Neurosurgeons, Radiation and Medical Oncologists
Hospitals
Various adult and paediatric cancer patient support groups

Discussions on Various Topics:

- Occupation - options
- Vocational Training
- Education support for siblings/ children of Brain Tumor affected.
- Psychological support and counselling
- Social Integration
- Financial security
- Yoga/ Sound healing/ Physical Fitness.
- Motivational Talk
- Meet professionals from various fields.

Email ID: btsgfoundation@gmail.com
Twitter: @awarenessbtsg 0755-2427804 (9am-5pm) Mobile: 9416224255, 7880063005
Bengaluru co-ordinator: Brjesh Deshpande, Mobile: +91 9896824904, Email ID: btsg.bengaluru@gmail.com

SECTION 8 NOT FOR PROFIT ORGANISATION




PHILIPPINES BRAIN TUMOR ALLIANCE

*** FOUNDED DIRECTORS ***
William Abbott-GBM survivor 13 yrs: Susan Abbott

**** VOLUNTEERS ****
Isa Pangilinan, Chris Locher

***** MEDICAL ADVISERS *****
Dr. Gerardo Legaspi, Dr. Santosh Kesari, Dr. Marlon Saria
Dr. Gerry Cornelio, Dr. Steven Bacalian, Dr. Roland Gigataras
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We are Childhood Brain Tumor Association of Taiwan.

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The Lithuanian Brain Tumour Patients and their Caregivers SOCIETY



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including patients, their
families, health care
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The Ocean and Sky
Children's Hospice
in Yokohama

The Ocean and Sky Children's Hospice in Yokohama, Japan

Hisato Tagawa, Representative Director, Yokohama Children's Hospice Project
and Vice-President Japan Brain Tumor Alliance

Japan is known as one of the countries with the highest medical technologies and a remarkably low perinatal mortality rate. But in the shadow of this bright reputation, there are approximately 20,000 children living with seriously life-threatening conditions (LTCs), such as childhood cancer, genetic, metabolic, or neurological diseases, who lack the necessary total care of the mind, body and the spirit that they need.

All children have the right to enjoy life to the fullest, regardless of their health condition. They grow, develop, and nurture dreams through playing, studying, experimenting, and interacting with other people. But children with serious illnesses who are often repeatedly hospitalized cannot have the same experiences that healthy children enjoy as a matter of course. These children and their families can become socially isolated, spending



Mr Hisato Tagawa, father of Haruka, and a driving force behind The Ocean and Sky Children's Hospice in Yokohama, Japan

most of their time either in a hospital or within their homes. Children's palliative care and the support system, which focus on the quality of life of the child and the

whole family has not kept pace compared to other countries.

That is why Yokohama Children's Hospice Project decided to take up the mission to advocate for the creation of a children's hospice, a place for children with serious illnesses and their families, where the time spent will be a shining memory forever.

The beginning

It was in early summer, 1997. My younger daughter, Haruka, had just turned six when she started to complain of a headache every morning. Soon, I noticed that she was dragging her right leg as she walked. My wife and I immediately took her to a general hospital, where we were given a shocking diagnosis. The doctor told us that: "Your daughter has an incurable brain tumour, DIPG [diffuse intrinsic pontine glioma]. She has about six months to live."

Five months later, my daughter passed away

The time spent with her in the final months made me think of the meaning of her life and I came to realize that the medical care for children in those days did not take into consideration the needs of the children and their families. In 2003, my colleagues and I started up a non-profit organization to provide non-medical support for the families of hospitalized children, building a house for family accommodation, as well as providing day-care for the siblings. It was a big step forward, but we continued to feel that there was still much to be done to support the children and their ➤



Young Haruka Tagawa from Japan was diagnosed with an incurable brain tumour when she was six years old



The Hospice's bright and airy main hall and the kitchen area on the ground floor

families to productively use the remaining time, to enhance childhood development, and to provide enduring support for the families throughout the journey, including bereavement.

Advocating for a children's hospice

It was during that time that I learned about the "children's hospice movement", which spread from the United Kingdom to the rest of the world. In Japan, "hospice" is often regarded as "the last resort" but I learned that a "children's hospice" is not a place of resignation but a "home" for those children and families, a place of comfort, rest, and above all, fun and enjoyment. My dream to create a children's hospice in Japan became stronger, and one day in 2014, we were surprised to receive a bequest of 105 million yen from a former nurse who had the same dream. This became a major driving force to start a new non-profit organization, the Yokohama Children's Hospice Project, to prepare for the creation of a children's hospice and to promote children's palliative care.

We set a goal to raise 300 million yen to finance the building of the hospice. Charity concerts and symposiums were organized to raise awareness and funding for the children's hospice, which was a concept still little known in Japan. Seminars and workshops were also held, involving medical, social welfare, and education sectors, as well as the local authorities and the general community, since cross-sectoral partnership and development of community resources are vital for the prevention of social isolation and alleviation of the burden of sick children and their families. Our efforts resulted in a gradual increase in the number of supporters and amounts of funding donated. The recognition and grants from the local authorities also allowed us to expand the scope of our activities.

Finally in 2019, we achieved the goal of 300 million yen, and at the same time, we were selected by Yokohama City as the organization to operate a "Nursing Care Support Facility for Children and Families Living with Life-Threatening Conditions" (a "Children's Hospice"). It meant an authorization to use the municipal land free-of-charge for 30 years, as well as



The National Children's Hospice Summit 2022. Mr Tagawa is third from the left.

five years of salary for a registered nurse. This was the moment when our dream became a reality! A children's hospice was to be born in Yokohama, Japan.

The Ocean and Sky Children's Hospice in Yokohama

During these years, we visited children's hospices in the UK, Germany, and the Netherlands to learn from their experiences. We remain truly grateful for the warm welcome and generosity they showed us, and for their willingness to share any information they thought would help us.

What we appreciated the most during these visits was the warm and welcoming atmosphere we felt the moment we stepped into the hospice facilities. That was what we wanted to recreate in Japan. Doctors, nurses, play specialists, occupational therapists, families, and architects gathered together to discuss the design of the building over and over again, so that people of all ages, with or without illnesses and disabilities, would be able to relax and enjoy their surroundings in their own ways.

The ground floor of our hospice - which we named "The Ocean and Sky Children's Hospice" (named after its location by the sea) - is built in a concrete frame as a protection from natural disasters. It is a public area, with a large multi-purpose hall and it contains a swing and a hammock for everyone to use. The dining and kitchen areas have counters

of different heights, accessible to children, adults and people in wheelchairs. A counseling room, a sitting room, and the staff room are also found on this floor. It is a welcoming space suitable for gathering, but also for private conversations.

The walls of our hospice have been painted in warm colours by our supporters and volunteers. Upstairs is a warm, wooden structure and it is an area where the families and guests can relax in privacy. There are three family bedrooms and a big family bathroom. A family bath is an important part of Japanese culture, and it was a request of many bereaved families. A hoist can be used to transfer a child from the bedroom to the bathtub and audiovisual devices provide sensory relaxation or stimulation. These facilities have been installed following the examples of the children's hospices we visited, and approximately nine million yen was raised by crowdfunding to provide these features. Many of the pieces of furniture and toys were donated to us.

The Ocean and Sky Children's Hospice in Yokohama, built with the support and loving thoughts of so many people, finally opened its doors on November 21, 2021.

Yokohama Children's Hospice Project today

Today, the Yokohama Children's Hospice project has two main pillars of activities.

The first pillar is the children's hospice itself, providing a safe and supportive ➤



The play area upstairs has room for lots of fun!



This bedroom at The Ocean and Sky Children's Hospice has a hoist



A family bathroom has audiovisual devices installed which provide sensory relaxation or stimulation

environment. The families can enjoy diverse activities together which they had always thought impossible, such as picnics, camping, baking, or bathing together. We are currently open only for day use, but we are preparing for the provision of accommodation in the future. Not only the sick child but the whole family is cared for at the hospice, making sibling support and bereavement support equally important.

The second pillar is the development of a community network. We organize seminars and workshops with medical, social welfare and education sectors to strengthen partnerships, and we also organize social events to engage the community, in order to create a socially supportive environment for the children and families living with LTCs.

Growing network of children's hospices in Japan

The children's hospice in Yokohama is a community-based, free-standing facility, that operates mainly on donations. There is only one other such facility in

the country. The high construction cost and the lack of an institutional support system and human resources in children's palliative care in Japan makes it difficult for others to follow suit.

Nevertheless, the need is there, and there is an increasing movement to create children's hospices in other parts of Japan too. There are currently two hospital-based children's hospices, and other organizations are preparing to create free-standing hospices in places such as Hokkaido, Tokyo, Fukuoka, Nara, Nagano and Fukui.

In February 2022, all of these organizations gathered together at a symposium "The National Children's Hospice Summit 2022", in recognition of the need to build a network to cooperate, exchange knowledge and experiences, and work in partnership to raise awareness and understanding. After the symposium, several individuals and groups have also shown interest in establishing children's hospices in their areas. The interest is spreading, and it will be increasingly important to join forces to advocate for and strengthen support to

ensure sustainable operation and financing of children's hospices in Japan.

Children live "in the moment"

Each child must appreciate their potential and not be limited by their illnesses or disabilities.

I dream of a mutually supportive society in which children living with life-threatening conditions and their families are not left isolated.

I believe that all the children, including my daughter Haruka, are asking all of us to build that supportive society. ■

For more information, please visit:
<https://childrenshospice.yokohama/index.html>
<https://childrenshospice.yokohama/english.html> (English)

Yokohama Children's Hospice Project,
 1-49-5 Mitsuura-higashi,
 Kanazawa-ku, Yokohama-shi,
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Providing survivors of hypothalamic-pituitary brain tumors with an improved quality of life by providing access to education, technology, and evolving treatments.

We support survivors and their caregivers and families.

We provide a source of much-needed information and education about these tumors and their comorbidities.

We advocate for research and innovation in treatment of these tumors to mitigate lifelong challenges.

We provide medical devices that may help with ongoing chronic conditions while developing innovations to improve management of care.

We serve as an interface between the medical and research community, survivors of these brain tumors, families and caregivers.



PROVIDING CRITICAL CARE

We have provided 25 hospital-grade handheld blood analyzers to pediatric brain tumor survivors suffering from adipsic diabetes insipidus.

Find out more at rawoodfoundation.org



TOGETHER WE THRIVE... EPIDERMID BRAIN TUMOR SOCIETY

The Epidermoid Brain Tumor Society was launched May 1, 2012.

The EBTS mission is to:

- ❖ Inform
- ❖ Educate
- ❖ Support
- ❖ Encourage
- ❖ Fund research for those affected by the epidermoid brain tumor.

EBTS is united in the belief that research will make the difference in the lives of those affected by this destructive brain tumor.

For more information, visit:

www.epidermoidbraintumorsociety.org

Epidermoid Brain Tumor Society (EBTS) is a 501(c)(3) organization

THE Nick Gonzales FOUNDATION for Brain Tumor Research



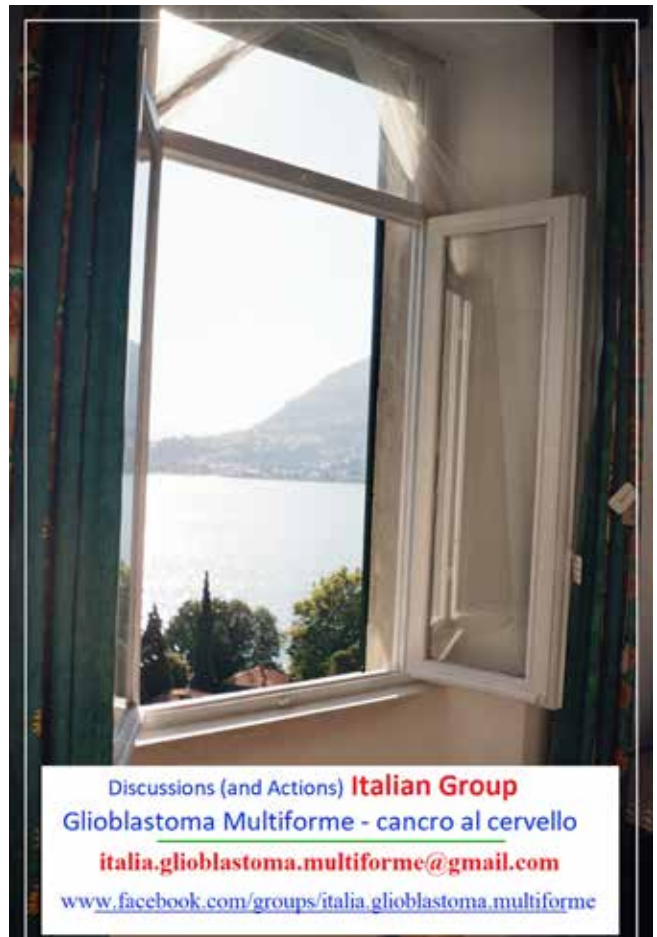
Our Mission

Increase awareness of the early warning signs of brain tumors and raise critical funds for targeted research that leads to earlier detection and better treatment options to improve the lives of those diagnosed with a brain tumor/cancer in the United States.

Proudly sponsoring the research of Dr. Karen Fink, Baylor Scott & White in Dallas and Dr. Sam McBrayer, Children's Hospital in Dallas, focusing on adult and pediatric brain tumors.



For more information, visit: www.TheNickGonzalesFoundation.org
nickgonzalesfoundation@gmail.com



Discussions (and Actions) **Italian Group**
Glioblastoma Multiforme - cancro al cervello
italia.glioblastoma.multiforme@gmail.com
www.facebook.com/groups/italia.glioblastoma.multiforme



Changing cancer care together

For All.Can, efficient cancer care delivers the best possible health outcomes using the human, financial, infrastructural and technological resources available, with a focus on what really matters to people with cancer and to society as a whole. Improving efficiency benefits everyone – including patients, carers, healthcare professionals, healthcare system managers, industry, governments, payers and the society at large.



Visit www.all-can.org to read our new policy blueprint "Building Efficiency in Cancer Care" which offers a broadly applicable framework to support collaborative policy action to improve efficiency in cancer care in ways that are people-centred and equitable.

PVW Brain Tumor Foundation

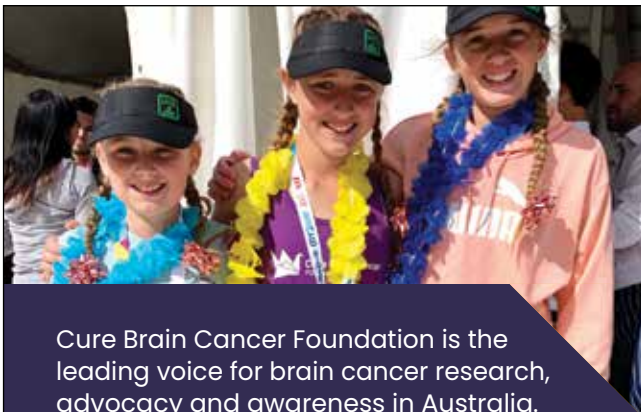


Based in Hong Kong, we ...

- raise awareness of brain tumors in the community, and
- provide support to those affected by brain tumors

You can find us at:

www.pvwbraintumorfoundation.org.hk



Cure Brain Cancer Foundation is the leading voice for brain cancer research, advocacy and awareness in Australia. We strive to rapidly increase brain cancer survival and improve the quality of life for people living with this disease – it's at the core of everything we do.

Our Vision

A cure for brain cancer.

Our Mission

Unite our community to increase brain cancer survival & quality of life.

curebraincancer.org.au




**Cure Brain
Cancer
Foundation**



Powered by [Head for the Cure Foundation](http://HeadfortheCureFoundation.org)

Through peer-to-peer connections, education resources, and advocacy opportunities, Brains for the Cure is providing real-time support to brain tumor patients and caregivers along their journey.

Learn more at brainsforthecure.org



In Honour of “Addy”

Chris Tse, Chair and Founding Trustee
Brain Tumour Support New Zealand

Eleven-year-old entrepreneur launches business in honour of her late grandmother, who passed away from brain cancer

Tyla-Jaz, or TJ to her family and friends, was just nine years old when she lost her beloved grandmother “Addy” to brain cancer in 2020.

As TJ describes, Addy was also her best friend: “We used to do lots of fun things together, like going to the mall, going on walks, playing games, and cooking together.”

“But one day we were at her house, and she was kind of sick because of the brain cancer so she had to go to hospital. When she went in the ambulance, I was so upset I was crying, and I couldn’t stop. When we went to go see her, she didn’t know she had brain cancer and neither did we, but then one day she got told the news that she was diagnosed with brain cancer.”

Like so many people who have faced a brain cancer diagnosis, Addy fought her illness bravely before sadly passing away in 2020.

In March 2021, TJ came up with the idea to launch her own business selling Fidget products. Fidget products are designed to help with stress, anxiety and enhancing children’s motor skills. A little over a month later, her business “TJ and Co” was launched. And in honour of Addy, TJ decided to donate a portion of all sales to Brain Tumour Support NZ.

TJ and Addy were very close, according to TJ’s mum, Paige who said: “TJ watched, experienced and lived through day one with my Mum all the way to the end of her journey, which lasted three years. All TJ wants to do is help other families in need and if she can donate towards making Brain Boxes for people at the end of the day that is what pushes her through her small business.”

A Brain Box is a care package from Brain Tumour Support NZ containing



TJ and her grandmother “Addy”

information guides and gifts for patients and carers. They are sent free to people anywhere in New Zealand who have been diagnosed with a brain tumour.

Now at the ripe old age of eleven, TJ works hard on her business, announcing the launch of new products, promotions and “bundle deals” on her website, and through

Facebook and Instagram. With the support of her loving whānau (the Māori word for “extended family”) and a growing customer base, TJ is determined to make a difference to families who are impacted by brain cancer.

Chris Tse, chair of Brain Tumour Support NZ, said: “We have never met someone quite like TJ. To face grief and loss at such



Eleven-year old Tyla Jaz, known to her family and friends as "TJ"

a tender age and turn it around to do something positive for others takes a person of special character and maturity. I'm sure Addy is looking down on her granddaughter with great pride and joy." ■

For more information about the work of Brain Tumour Support New Zealand, please visit their website at: <https://www.braintumoursupport.org.nz/>

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TJ is already a media veteran having appeared on local radio and TV spots



TJ dispatching the latest orders to her online customers



TJ works hard on her business "TJ and Co"




Rare Cancers Europe
Joining forces for action

Rare Cancers:

- » More than 5.1 million people in Europe live with a rare cancers*
- » Rare cancers correspond to 650.000 new diagnosis in Europe**
- » Rare cancers represent the 24% of all new cancer diagnosis in Europe**
- » Estimated 5-year relative survival is significantly lower for rare cancers than for their common counterparts (48.5% and 63.4% respectively)***

Rare Cancers Europe is a multi-stakeholder partnership initiative addressing methodological and regulatory barriers in rare cancer care, the need for centres of expertise and European Reference Networks, barriers to patients' access to care, education of healthcare professionals and access to information on rare cancers. For more information, please visit www.rarecancerseurope.org.

*Source: [https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/POI_STU\(2020\)6423](https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/POI_STU(2020)6423)
**Source: <https://pubmed.ncbi.nlm.nih.gov/22033>
***Source: <https://www.sciencedirect.com/science/article/pii/S147020451730445X?via%3>




Brain Tumour Foundation of India

1129, Homi Bhabha Block
Tata Memorial Hospital
Parel, Mumbai 400012, INDIA
Phone: +91-22417700 Extn: 6020
braintumorfoundation.india@gmail.com

Brain Tumour Foundation of India

● Detection ● Treatment ● Rehabilitation ● Care ● Support ● Hope

GIVE WINGS OF INDEPENDENCE TO WOMEN TO FLY HIGH & HIGH



the GRAY MATTERS foundation



We are about **Support.** NOT STATISTICS.

BRAIN TUMORS STINK!

THAT'S WHAT WE THINK!

We're here to SUPPORT you on your brain tumor journey with:

- ♥ Support groups
- ♥ Patient advocacy
- ♥ Personal outreach
- ♥ Resources for families

Connect with us today.   

LEARN MORE @ WWW.GRAYMATTERSFUNDATION.ORG



IHI A RANGI NZ Brain Tumour Trust

NZBTT is a charitable trust which recognises the need for patient and research support in New Zealand, and aims to make a real and positive difference to the lives of people of all ages diagnosed with a brain tumour.

The Trust seeks to promote a culture of healing, wellbeing, and support at all stages of an individuals' experience with a brain tumour, both cancerous and benign, also supporting their family and whānau.

The Trust also aims to help brain tumour patients by underwriting research, providing funding, and encouraging the newest therapies to New Zealand through clinical trials.

Through Ihi a Rangi New Zealand Brain Tumour Trust, we seek to bring the promise of better therapies, care, and cure.

   [@nzbraintumourtrust](https://www.nzbttr.org.nz) www.nzbttr.org.nz

International Brain Tumour Awareness Week Bucaramanga, Colombia

Gabriel Vargas MD,

Honorary President of the Neurological Oncology Section of the Latin American Federation of Neurosurgical Societies (FLANC) and lead coordinator of the XI Symposium

Activities in Bucaramanga, Colombia continue to support this event despite the COVID-19 pandemic during 2020 and 2021.

For the eleventh year running we supported the International Brain Tumour Awareness Week 2021 with three great events.

Event One – an in-person, pre-symposium course

We organized a pre-symposium practical course in person, on the use of Ultrasound Intraoperatively in Neurooncology addressed to neurosurgeons of Bucaramanga and residents and professors of the neurosurgery program of the Hospital Militar Central (Bogota DC) as special guests of the event and as part of their academic event called “Tertulia Neuroquirúrgica”. The course was coordinated by radiologist Camilo Lara MD, Andres Vargas MD, and Gabriel Vargas MD, held at Hospital Universitario Los Comuneros.

Event Two – a dinner talk

A dinner talk was organized between neurosurgeons all over the city and neurosurgery residents from the Hospital Militar Central. The use of new strategies in neuro oncology was the main topic of discussion and it helped to create strategies for multidisciplinary treatment of our patients.

Event Three – the XI International Brain Tumor Awareness Day Symposium

On November 6, 2021, we held the XI International Brain Tumor Awareness Day Symposium at the Universidad de Santander (UDES) with the participation



of 60 participants in person (COVID-19 restrictions still applied) and more than 350 online participants. Physicians, health

personnel interested in the topic, students, brain tumor patients and their families attended the event. ➤



Participants at the XI International Brain Tumour Awareness Day Symposium included neurosurgery research group students from UDES and residents and professors of the neurosurgery program of the Hospital Militar Central (Bogota DC)



Pre-Symposium practical course in ultrasound for the management of brain tumors. Juan Luque MD, Chief of Neurosurgery at the Hospital Militar Central is shown practicing with the specimens

We had a great scientific symposium with the support of world class speakers from around the globe including Latin America, Europe and the United States. Specialists gave lectures during the day discussing diagnosis, current treatments and care of patients with brain tumors. The speakers who supported our event

during the academic agenda were Dr. Fernando Martinez (Uruguay), Dr. Marcos Maldaun (Brazil), Dr. Hughes Duffau (France), Dr. Joerg-Christian Tonn (Germany), Dr. Miguel Arraez (Spain), Dr. Paul Gardner (USA) and Dr. Tito Vivas (USA).

All the activities were supported by Universidad de Santander (UDES) and

its medical faculty; Clinica Chicamocha; Hospital Universitario Los Comuneros; Society for Neuro-Oncology Latin America (SNOLA); the neurooncology and skull base section of the Colombian Association of Neurosurgery (ACNcx); the neurooncology section of the Federacion Latinoamericana de Neurocirugía (FLANC); and different commercial partners involved in the treatment of patients with brain tumours.

The event was free for everyone. The entire event can be viewed on YouTube. Search for "XI Simposio Día Internacional de Concientización de Tumores Cerebrales". ■

Did you receive *Brain Tumour* magazine in a personally addressed wrapper?

If you did, then you are on our database. However, if you received the magazine but do not receive our regular e-News bulletins it means that we do not have your email address.

If you would like to receive the monthly e-News bulletins please complete our subscription form at <https://theibta.org/our-publications/#e-News>

The Brain Tumour Patients' Charter of Rights

The *Brain Tumour Patients' Charter of Rights* is intended to address brain tumour inequalities across countries. It is also meant to simulate debate and discussion. We hope that the *Charter* goals are shared by us all, whether we are brain tumour patients, caregivers, advocates, healthcare professionals or policymakers.

The *Charter* was launched in 2020 and is currently supported by over 90 organisations around the world.

Please let us know if you would like to come on board as a supporting organisation by contacting kathy@theibta.org

The *Charter* is designed to be relevant across the globe and to this end, we at the IBTA have also started a programme of translating it into as many languages as possible. This will maximise the impact of the *Charter* and help broaden accessibility to it.

To date, the *Charter* has been translated from the English version into 14 languages: Catalan, Chinese (Traditional), Chinese (Simplified), Danish, French, German, Greek, Italian, Japanese, Polish, Portuguese, Spanish, Swedish and Urdu. Norwegian and Hindi are in the translation pipeline.

To further maximise dissemination and use of the *Charter* around the world, we warmly welcome volunteers to translate the *Charter* document into additional languages not yet covered.

Guidelines for translators can be downloaded from the IBTA website at www.theibta.org

If you are interested in helping us translate the *Charter*, please contact kathy@theibta.org

We'd love to hear from you! ■



Brain tumour patient and caregiver advocacy, support, fundraising and information organisations and initiatives

AUSTRALIA

ACT Brain Tumour Network

Email btaa@shout.org.au
or call Susan on 0404255156

Adult Brain Cancer Support Association

adultbraincancersa@gmail.com <https://www.facebook.com/AdultBrainCancerSA?fref=nf>

Australian Pituitary Foundation

<http://www.pituitary.asn.au/>

Brain Tumour AhoyHoy

<http://www.braintumourahoyhoy.org/>

Brain Tumour Alliance Australia (BTAA)

www.btaa.org.au

Brain Tumour Association Western Australia

braintumourwa@hotmail.com
<http://www.btawa.com.au/>

Brain Tumour Support Group - Cancer Council Queensland

<https://cancerqld.org.au/get-support/>
or <https://cancerqld.org.au/get-support/cancer-emotional-support/brain-tumour-support/>

Cure Brain Cancer Foundation

<http://www.curebraincancer.org.au>

Grey Matters

www.greymatters.org.au

Mark Hughes Foundation

<https://markhughesfoundation.com.au/>

Neuro-Oncology Information Network - NOgin

<http://www.sydneybrainandspinesurgeons.com.au/nogin.html>

Newro Foundation

<http://www.newrofoundation.com.au/>

Peace of Mind Foundation

<http://www.peaceofmindfoundation.org.au>

Robert Connor Dawes Fund

<http://rcdfoundation.org/>

United Brain Tumour Support

Contact Pete McLaughlin:
(Australia) 0422 784885.
Listing here also: <http://www.yourcare.com.au/supplier/profile/united-brain-tumour-support>

BELGIUM

Can cé tu

<http://www.cance-tu-asbl.eu>

Werkgroep Hersentumoren

<http://www.wg-hersentumoren.be>

CAMEROON

Jacob's Hope Foundation

<https://www.facebook.com/Jacobs-Hope-Foundation-for-Brain-tumours-and-othercancers-1735452683351613/>

CANADA

BC Cancer Agency

<http://www.bccancer.bc.ca>

B-Strong

<http://www.bstrong.ca>

b.r.a.i.n.child

<http://www.sickkids.ca/Brainchild/index.html>

Brain Tumour Foundation of Canada

www.braintumour.ca

Gerry and Nancy Pencer Brain Tumor Centre

<http://www.pencerbraintrust.com/>

Meagan's HUG

<https://www.meaganshug.com/>

Tali's Fund

www.taldoron.com

CAYMAN ISLANDS

Brain Tumour Foundation (Cayman Islands)

"The Forgotten"

<https://www.facebook.com/pg/bftcaymanislands/posts/>

CROATIA

Croatian Brain Tumor Association - GLIA

www.glia.hr

CYPRUS

Cyprus Brain Tumour Association (CBTA)

<https://www.facebook.com/cbta.cyprus>

DENMARK

HjernetumorForeningen

<http://www.cancer.dk/hjernetumorforeningen/>

FRANCE

Alinoe

(Association Lilloise de Neuro-Oncologie)
www.alinoe.asso.fr

ARTC Paris

<http://www.artc.asso.fr/>

ARTC Sud

www.artcsud.fr

ARTC Toulouse – Midi Pyrenees

<http://www.artc.asso.fr> Association Léa Princesse

Eternelle

<http://leapourlavie.free.fr/>

GFME Glioblastoma Foundation

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

Gemeinsam gegen Glioblastom

www.gemeinsamgegenglioblastom.eu

yeswecan!cer

<https://yeswecan-cer.org/>

HONG KONG

The PWV Brain Tumor Foundation

www.pwvbraintumorfoundation.org.hk

INDIA

Brain Tumour Foundation of India

www.braintumourindia.org

BTSg Awareness Foundation India

(Brain Tumor Support Group and Awareness Foundation)

www.btsfoundation.in

IRELAND

Brain Tumour Ireland

<http://www.braintumourireland.com/bti/>

The Irish Brain Tumour Support Group

www.braintumoursupport.ie

ISRAEL

ILAM –

the Israeli Brain Cancer Association

www.ilam.org.il

ITALY

Associazione Italiana Tumori

Cerebrali ONLUS

<http://www.tumoricerebrali.it/>

BrainLife

www.brainlife.org

Brainy

www.associazionebrainy.com

Fondazione Heal
www.progettoheal.com

Glioblastoma.IT
www.glioblastoma.it
www.glioblastomamultiforme.it

Il Fondo di Gio ONLUS
www.ilfondodigio.it

Il laboratorio di Chiara
<https://www.illaboratoriodichiara.org>

IRENE Onlus
<http://www.associazionerene.it/>

Italia - Glioblastoma Multiforme - cancro al cervello
<https://www.facebook.com/Italia-Glioblastomamultiforme-cancro-al-cervello-57560022151/>

Oscar's Angels Italia
<https://www.oscarsangelsitalia.com>

JAPAN
Japan Pediatric Brain Tumor Network
www2.pbtn.jp

Japan Brain Tumor Alliance
<http://www.jbta.org>

KENYA
Brain Tumour Association of Kenya (BTAK)
<https://www.btak.org/>

LEBANON
CHANCE - Children AgaiNst CancEr
<http://www.beirut.com/l/25407>

LITHUANIA
Kartu Lengviau
www.kartulengviau.lt/joomla/pradzia.html

Lithuanian Brain Tumour Patients and their Caregivers Society
Phone: +370 37 326694

NETHERLANDS
Hersentletsel.nl
<http://www.hersenletsel.nl>

Hersentumor.nl
<http://hersentumor.nl/>

Hersentumorfonds
<https://hersentumorfonds.org/>

Hersentumoren.info
<https://hersentumoren.info/>

Sterk en Positief
www.Sterkenpositief.nl

STOPhersentumoren.nl
www.stophersentumoren.nl

NEW ZEALAND
Brain Tumour Support New Zealand
<https://www.braintumoursupport.org.nz/>

New Zealand Brain Tumour Trust
www.nzbtt.org.nz

NORWAY
Hjernesvulstforeningen
www.hjernesvulst.no

PAKISTAN
Brain Tumour Foundation of Pakistan
In partnership with the Pakistan Society of Neuro-Oncology
www.braintumour.pk

PHILIPPINES
Philippines Brain Tumour Alliance
<http://www.facebook.com/pages/Philippine-Brain-Tumor-Alliance/139492062749160/>

POLAND
Glioma Foundation Center
<https://glioma-center.com/en/main-page/>

SINGAPORE
Brain Tumour Society (Singapore)
<http://braintumoursociety.org.sg>

SOUTH AFRICA
Rainbows and Smiles
<http://www.rainbowsandsmiles.org.za>

SPAIN
Asociación 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.hjartumorföreningen.se

SWITZERLAND
Kinderkrebs Schweiz
<http://www.kinderkrebshilfe.ch>
Schweizer Hirntumor Stiftung (Swiss Brain Tumor Foundation)
<http://www.swissbraintumorfoundation.com>

TAIWAN
Childhood Brain Tumour Association of Taiwan (CBTA)
<http://www.cbta.org.tw>

TURKEY
Türkiye Beyin Tumoru Hasta ve Yakınları Derneği (Brain Tumour Patient & Caregivers' Association of Turkey)
<https://www.facebook.com/tbthyd/>

UGANDA
Uganda Brain Tumour Foundation
<http://www.ubtuf.org>

UNITED KINGDOM
Ali's Dream
www.alisdream.co.uk
Andrew McCartney Trust Fund
www.andrewmccartneyphotos.co.uk

Anna's Hope
www.annashope.co.uk

Astro Brain Tumour Fund
www.astrofund.org.uk

Brain and Spine Foundation
www.brainandspine.org.uk

Brain Tumour Action
www.braintumouraction.org.uk

Brain Tumour Research
www.braintumourresearch.org

Brain Tumour Research and Support Across Yorkshire
<http://www.btrs.org.uk>

Brain Tumour Research Campaign
<http://www.wayahead-btrc.org/>

Brain Tumour Support
www.braintumoursupport.co.uk

Brain Tumour Support Group - St Thomas' Hospital, London
<http://www.guysandstthomas.nhs.uk/our-services/cancer/cancer-types/brain/patients.aspx>

Brainstrust
www.brainstrust.org.uk

Brainwaves Brain Tumour Support Group
<http://www.brainwavessg.co.uk/>

Brainwaves NI (Northern Ireland)
www.brainwaves-ni.org

British Acoustic Neuroma Association - BANA
www.bana-uk.com

Clowns in the Sky
<http://www.clownsinthesky.org/>

Fighting Ependymoma (The Chris Bramhall Children's Brain Tumour Research Charity)
<https://www.fightingependymoma.org.uk/>

Headcase
www.headcase.org.uk

Katie McKerracher Trust
www.katiemckerrachertrust.co.uk

Levi's Star
<http://www.freewebs.com/levisstar/>

Naseem's Manx Brain Tumour Charity
<http://www.naseemsmxbraintumourcharity.co.uk/>

PPR Foundation
<http://www.thepprfoundation.com/>

Spinal Cord Tumour Forum
www.spinalcortumour.org.uk

Success Charity
<https://successcharity.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

UNITED STATES**Addi's Faith Foundation**

www.addisfaithfoundation.org

Adult Ependymoma

<https://sites.google.com/site/adultependymoma/>

A Kid's Brain Tumor Cure (AKBTC)

<http://akidsbraintumorcure.org>

American Brain Tumor Association (ABTA)

www.abta.org

Angels Among Us

https://secure3.convio.net/dccc/site/TR/Angels/AngelsAmongUs?pg=entry&fr_id=1530

Ben and Catherine Ivy Foundation

www.ivyfoundation.org

Benny's World

<http://www.bennysworld.org/>

Brad Kaminsky Foundation

www.tbkf.org

Brain Science Foundation

www.brainsciencefoundation.org

Brain Tumor Foundation

www.braintumorfoundation.org

Brain Tumor Network (BTN)

<http://www.braintumornetwork.org>

Brain Tumor Support Group

of Northeast Florida <http://resources.caregiver.com/listing/brain-tumor-support-group-of-northeast-florida.html>

Brains Together for a Cure

www.brainstogetherforacure.org

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**

- CNJBTSO

www.njbt.org/startCNJBTSO.cfm

Childhood Brain Tumor Foundation

www.childhoodbraintumor.org

Children's Brain Tumor Foundation

www.cbtf.org

Chordoma Foundation

<http://www.chordomafoundation.org>

Collaborative Ependymoma**Research Network (CERN) Foundation**

<http://cern-foundation.org>

Cullather Brain Tumor**Quality of Life Center**

<http://cullather.org/>

Dr Mamie Rose Foundation

www.drmamierose.org/

<https://www.facebook.com/drmamierosefoundation/>

EndBrainCancer (Chris Elliott Fund)

www.EndBrainCancer.org

Ependyaparents online support group

<http://braintrust.org/groups/ependyaparents/>

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/>

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 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://thenickgonzalezfoundation.org/>

OligoNation

www.oligonation.org

OurBrainBank

www.OurBrainBank.org

Pediatric Brain Tumor Foundation

<http://www.curethekids.org/>

Raymond A Wood Foundation

<https://www.rawoodfoundation.org/>

ROC On! Run Over Cancer

<https://www.facebook.com/pages/category/Nonprofit-Organization/ROC-on-Run-Over-Cancer-310235803819/>

<https://www.facebook.com/pages/category/Nonprofit-Organization/ROC-on-Run-Over-Cancer-310235803819/>

San Diego Brain Tumor Foundation

www.sdbtf.org

Sontag Foundation

<https://sontagfoundation.org>

Southeastern Brain Tumor Foundation

<http://www.sdbtf.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.voicesagainbraincancer.org

ZIMBABWE**Zimbabwe Brain Tumor Association (ZBTA)**

<https://www.facebook.com/Zimbabwe-Brain-Tumor-Association-225796887464934/>



INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

29th October - 5th November 2022

The IBTA requires no financial commitment from your organisation to be a supporter.
Contact kathy@theibta.org

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Thank you!

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