



THE OFFICIAL BTAA MAGAZINE

INTERNATIONAL BRAIN TUMOUR
AWARENESS WEEK EDITION

OCTOBER 2020 EDITION

BTAA.ORG.AU

THE BRAIN
TUMOUR PATIENTS'
CHARTER
OF RIGHTS



International Brain Tumour Patients' Charter Released

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NEED SUPPORT NOW?

PHONE 1800 857 221



To talk with experienced caregivers, call BTAA on the Support number: **1800 857 221**, and see the support groups available in your local area at www.btaa.org.au – look for support organisations.

Cancer Connect telephone (**13 11 20**)

Brain Tumour Patients Telephone Support Group Support Line **1300 755 632**
Monday - Friday 9am - 5pm
or email tsg@nswcc.org.au

Cancer Connections (online)
www.cancerconnections.com.au

Email btaa@shout.org.au to enquiries@btaa.org.au

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We are always looking for more helpers and representatives, especially in regional areas and states that currently do not have representation.

LETTER FROM THE CHAIR

What a strange year it has been. The highs and the lows. This time last year I was privileged to attend, and by invitation, the International Brain Tumour Alliance (IBTA) 4th World Summit in Bethesda, Maryland, US from 9-12 October. Brain tumour patients, caregivers, researchers, clinicians and leaders of various brain tumour initiatives came together to share ideas and strategies to improve the care and well-being of those living with a brain tumour. Presentations ranged from brain tumour treatments and updates on research, to discussions about patient's perspectives. It was so inspiring to meet the people who are involved in this work, and to observe the passion that they bring to their efforts.

The Cooperative Trials group for Neuro-Oncology Conference (COGNO) was held in Sydney 27-29 October 2019. BTAA arranged a brain cancer Patient Education and Support Forum on the Sunday, with several international speakers sharing the latest developments with those in attendance. Topics included Advances in Neurosurgery, Neuro-imaging, Meningioma Management, Supportive Care, Systemic Therapy and Driving with Brain Cancer. These talks can be accessed on our website.

<https://btaa.org.au/resources-support/related-links>

Each year at COGNO since 2018, the BTAA Lynette Williams Award is announced for the best poster presentation focussed on support and care for brain tumour patients. First prize in 2019 was awarded to Ms Dianne Legge for her Abstract *"Building the Bridge: The value of consumer co-design in brain cancer resource development."* This information is available in a book, *Finished Your Treatment - What's Next?*, and can be viewed here <https://buildingthebridge.com.au>.

The second prize was awarded to A/Prof. Michael Back for his abstract *"Reflecting on survivorship outcomes to aid initial decision-making in patient managed for IDH-mutated Anaplastic Glioma."* There are sufficient funds for the award to be presented for ten years.

In March 2020, because of COVID-19, we cancelled all forums planned or supported for Brain Cancer Action Month in May. Forums were planned in Brisbane, Sydney, Canberra, Tasmania and Adelaide. We were very disappointed the forums could not proceed as they have benefited many brain tumour patients and their families in previous years. A Brain Cancer Patient Education & Support Forum held at the Wesley Sydney May 2019 can be viewed on our website <https://btaa.org.au/resources-support/related-links>



BTAA are extremely grateful to the doctors, nurses and health professionals who freely give of their time at these forums.

Our organisation is run exclusively by volunteers. By the time you receive this e-News, our AGM will have taken place with a new executive and committee elected. I would like to extend my thanks to the outgoing committee. In a photo from last years meeting some of the committee could not be present in person, including Catherine Baldwin, Diane Dunn and Alice Parsons <https://btaa.org.au/about/our-people>

We are always in need of more volunteers in all states to spread the word of the support available through BTAA. If you are interested in being involved, I would be delighted if you would contact me at chair@btaa.org.au

I wish everyone:- patients, carers, families, doctors, nurses, health care workers, brain tumour researchers and brain tumour support groups a happy and healthy 2021. Let's hope that COVID-19 is under control and we can enjoy seeing our families and friends interstate and overseas.

As many of you would be aware, there are a lots opportunities lately for researches, clinicians and nurses to apply for grants into supportive care of brain tumour patients and their carers. BTAA has been asked by several working groups to either partner or support applications for research grants. We also have had requests that requires input from brain tumour patients and carers and we have emailed our subscriber list requesting you participation. Thank you so much for responding the researchers are extremely grateful.

Catherine Hindson
Chair 2019-2020



Catherine is a retired registered Nurse whose daughter was diagnosed with a Anoplastic Astrocytoma in 2010. Her daughter is now doing extremely well although Catherine recently lost her husband Bill, also a great supporter of the BTAA, from a different form of cancer. Catherine is a keen birdwatcher, gardener and volunteers a great deal of her time to the BTAA to ensure that every person with a brain tumour has all of the support and information that they need.

My Cancer Journey

Harry Parsons

It was May 2015 when I (28 years old) discovered that there was an evil little lump of unwelcome matter that had taken up residence in my brain. I was on a weekend away from my new life in the Mediterranean to attend the wedding of some dear friends in Greece. I woke my bedmate when having a violent seizure that quickly woke the rest of our friends in the villa as well. Unfortunately, Santorini doesn't have its own hospital so it was deemed necessary that I was airlifted back to Athens. Of course I didn't have travel insurance, but in my crazy new life it wasn't unexpected to have friends with nearby pilots in the family. I was taken to Athens, where, after many days of needles and scans, the doctors at last concluded I had a tumour in my right frontal lobe which needed prompt attention. By this time my parents had arrived from Sydney and the doctors gave us the option of undergoing surgery there in Athens, or returning to my Motherland. We decided it best to go home.

I was delivered straight to the hospital where the doctors agreed that, yes, I had a tumour, and it was in fact a stage 2 diffuse Astrocytoma that did indeed need to be resected ASAP. Of course, neurosurgeons aren't simply on call and I had to wait a few weeks before going under the knife. This surgery was successful in that a good portion of the tumour was removed. I did, however, suffer a stroke and woke from surgery unable to move any limb or digit on my left side. I was extremely fortunate that my face and speech were unaffected, as is the case with many strokes.

I continued with regular MRIs until eventually a change presented itself on the scans two years after surgery number 1. At this time we sought a second opinion and possible alternative surgeon after the bad luck with the first, and she advised that this change in my images needed to be investigated more closely (ie a biopsy) and hey, while we're in there why not scrape out the rest of the tumour? Not only this, but Dr. 2 said she could remove the area of brain affected by the



stroke and likely relieve me of the seizure activity that had been troubling me.

The second surgery was a huge success in resecting almost all of the remaining tumour, but more importantly for me I no longer had to take the seizure medication that had been causing me (and everyone else around me) so much stress and discomfort. It did however, come with some bad news – the change in the scans was because the tumour had turned cancerous, (Anaplastic Astrocytoma) so the journey was far from over; I even managed to fit in a pulmonary embolism 5 days after surgery. From there I underwent both radiotherapy and chemotherapy, both of which are incredibly unpleasant; but in time the scans showed less and less tumour until ultimately there was nothing to see.

There is no cure for cancer, but I beat it, and there is a long list of medical professionals who deserve my endless gratitude, but the people who really got me through this horrible ordeal are my family and friends. Without such a strong network bolstering my hope and confidence I'd have given up years ago. Mind set is so important, and for most of this journey I was stubbornly certain I was going to walk away from it, but when that façade cracks there is no value that can be placed on the support of those who care about you.



Sunshine Beach State School Gets Behind the BTAA

The Sunshine Beach State School has raised \$1,246 for the Brain Tumour Alliance Australia. The money was raised by a gold coin donation activity 'Beanie for Brain Cancer' day this term.

Many thanks to all of the students and hard working teachers who organised this event.

Ependymoma Treatment Stalled By COVID

Rachel Thorpe lives in Canberra and is married to John, with three children. She has been diagnosed with both an Ependymoma and a Meningioma, and was treated in Australia as well as seeking treatment in new research programs in the USA. Ependymomas are very rare, with an occurrence rate much less than 1 per 100,000. Despite the sometimes debilitating effects of her tumours, Rachel also leads community initiatives, raises funds for the BTAA and brain tumour research, and runs a popular Facebook page.

Rachel Reports on her recent travels to the USA:

This time last year when I first wrote for the magazine I was getting ready to fly to Bethesda, Maryland to be assessed at CERN [Collaborative Ependymoma Research Network]. In March of this year my husband and I had planned our second visit. I'm currently enrolled in a Natural History Study at CERN which is a part of NIH [National Institute of Health] and NCI [National Cancer Institute]. This requires me to visit the clinic once every 12 months for assessment and a MRI; it also means that when I'm ready, they will operate to remove my C3/4 intramedullary ependymoma if I so choose. All of the medical care is provided at no cost, and they even cover our flights from LA. If and when the ependymoma recurs, I'll also qualify for an immunotherapy trial there. I consider myself extremely lucky to be in this programme. Meanwhile my meningioma is still on watch and wait.

Recently I was approached by SBS Insight to appear on an episode they are filming around difficult medical decisions. After I accepted, we discovered filming was occurring while we were in the US. So SBS organised a car to pick us up from the hotel, and take



Rachel and John in Las Vegas

us to a TV studio, where they have rented satellite time; I feel like a bit of a movie star! The interview went well, however a few days later as we were preparing to fly to the East Coast for my clinic visit, the whole world landscape changed due to COVID-19. Flights were cancelled, borders locked down and DFAT told Australian citizens to fly home. I then received an email telling me that due to the crisis my clinic appointments had been cancelled. So John & I made the very difficult decision to fly home from the US while we still could. In the end we only spent 6 days in the US and didn't achieve what we went for, but John got to see the majesty of the Grand Canyon for the first time, so not a wasted trip!

A lot has changed in the last 12 months. I've written a bucket list that comprises of 3 things:

- 1. Renew our wedding vows every year**
- 2. Help get a free street library in every suburb of Canberra**
- 3. Raise \$50,000 for brain tumour charities**

So far we're on target! John and I renewed our vows for our first anniversary in September 2019

by Lake Ginninderra. This year's plan is in New Zealand with my family. Belconnen Community Council have helped out with a grant that has enabled 3 street libraries to be installed, with 3 more in the works. \$8400 was raised in 2018 for BTAA; \$1600 in 2019 for Cure4braincancer and funds raised this year will go to Peace of Mind Foundation.

Fatigue, headaches and large amounts of pain, mean I haven't worked since June 2018, which also equals boredom. So in July of that year I started writing a blog on Facebook: The Plumber, His Missus, & Her Brain Tumours. Initially it began as a way to keep friends and family updated on where I was at. But now that it has grown to around 500 followers. I also use it to raise charity funds and awareness, particularly trying to get across the 'Benign Ain't Fine' message.

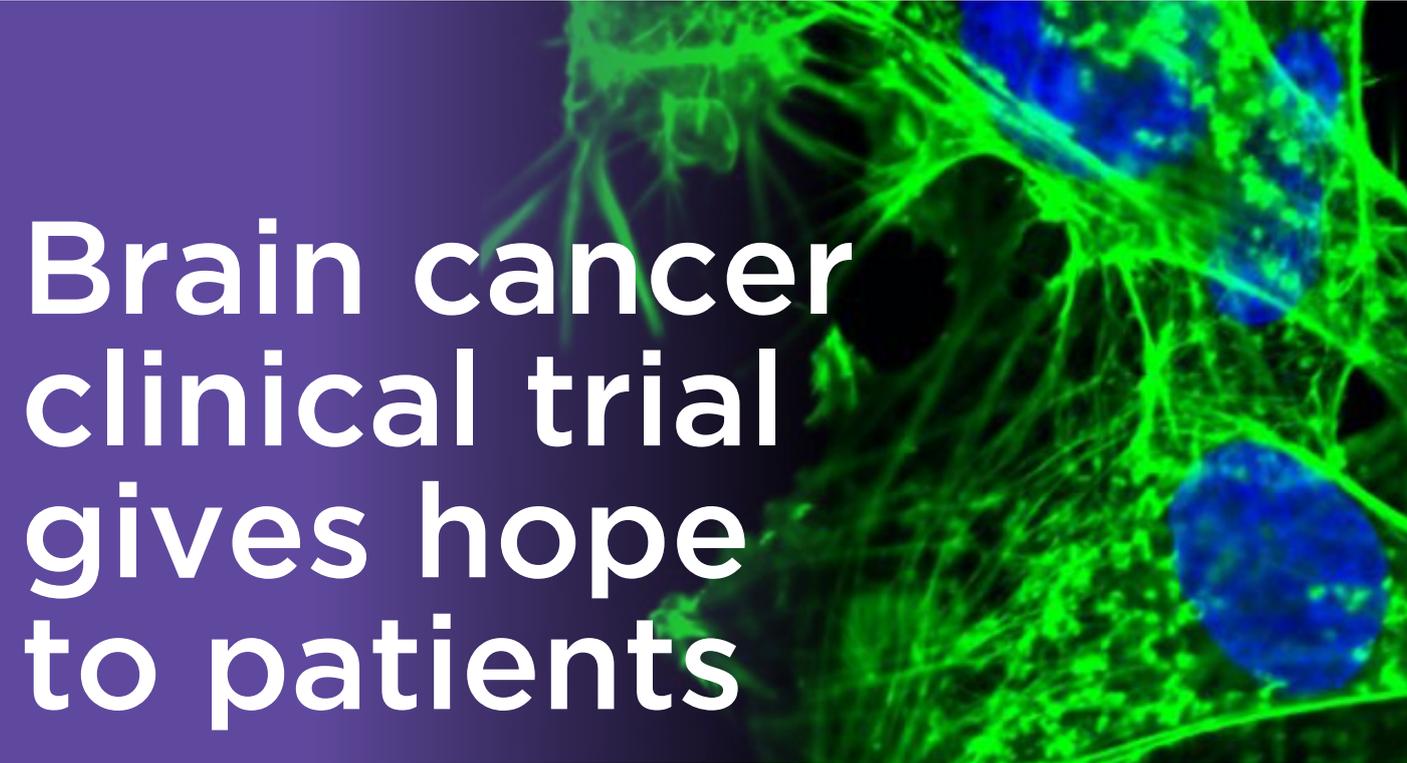


Rachel and John at the Grand Canyon

My walking is getting wobblier, so this year will see us hopefully sell our large split level house, and downsize to something smaller and one level. We're also considering a relocation to the South Coast. While Canberra has a lot to offer, the ocean is something I sorely miss. Additionally, I have found Canberra a hard place to gain a foothold in socially as it's not overly friendly at times.

I'm not sure what the next 12 months will bring, but I remain thankful for the amazing people I've met; the love of family in Australia and New Zealand; and the support of organisations like BTAA.

Rachel Thorpe



Brain cancer clinical trial gives hope to patients

Queensland researchers have found that patients who received a cellular immunotherapy for the deadly brain cancer glioblastoma multiforme (GBM) in a clinical trial on average survived longer than would have been expected without the treatment. The team also found the treatment was safe and identified clues that will help them improve it in future. The results of the phase I clinical trial have been published in the *Journal of Clinical Investigation*.

GBM is the most common malignant brain tumour in adults. It is a particularly aggressive cancer that usually recurs quickly after treatment. Patients survive an average of 14-17 months after diagnosis.

The cellular immunotherapy was developed by the head of QIMR Berghofer's Centre for Immunotherapy and Vaccine Development, Professor Rajiv Khanna AO, and his team. It was tested in a phase I (safety) clinical trial of 25 patients at Briz Brain and Spine in collaboration with neurosurgeon Professor David Walker. Professor Khanna said the patients were given the immunotherapy as a supplementary treatment after receiving surgery, chemotherapy and/or radiation.

"At the end of this clinical trial, 10 patients were still alive and five of those still had no signs of their cancer recurring," Professor Khanna said. "The 25 patients who received the treatment survived for an average of 21 months. This is an improvement on the current survival rates. "The results were even better in the 20 patients who received the immunotherapy before their tumours had recurred. Those patients survived for an average of 23 months, which is six to nine months better than we would have expected without this treatment. "Considering GBM is a highly deadly cancer, these are very promising results."

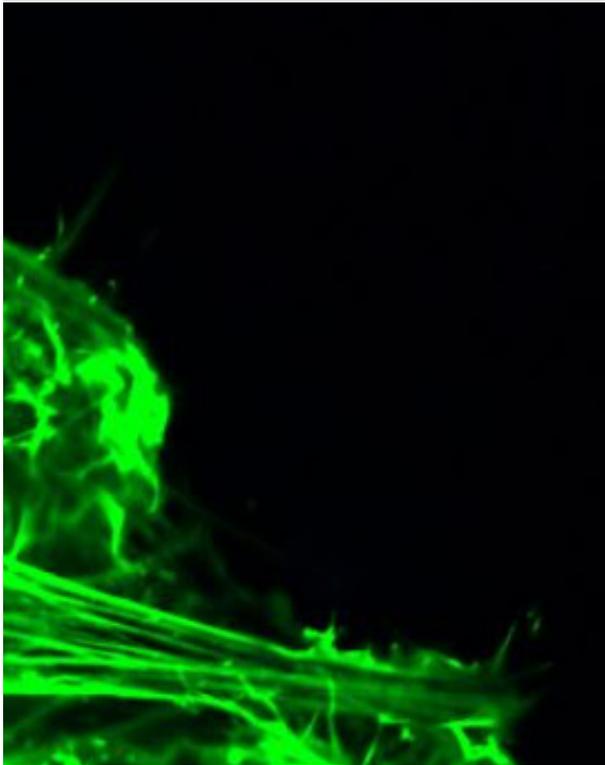
Neurosurgeon Professor David Walker said the trial had confirmed the treatment was safe for use in GBM patients.

"None of the patients experienced any adverse effects from the immunotherapy, which gives us confidence in progressing further clinical trials," Professor Walker said. "We have previously conducted another clinical trial where we gave this treatment to patients after their GBM had already recurred following initial treatment. "While that earlier trial prolonged survival, in this trial, we were excited to

see that some patients who received the immunotherapy earlier, before recurrence, had further improvements in survival. "Brain cancer survival rates have hardly changed in decades. This trial gives us hope that we might be on the cusp of changing that."

The cellular immunotherapies are produced by taking blood samples from patients and 'turbo-charging' their immune cells, known as T cells, in the laboratory to recognise and destroy the cytomegalovirus (CMV), which is present in the tumour cells.

Professor Khanna said they found the patients who survived had better T cell immunity to the cytomegalovirus. "The treatment each patient received was produced with their own immune cells. "We did a genomic analysis of each patient's immunotherapy and found that patients with certain gene signatures inside their immune cells had better results. "This is important because it tells us what improves the quality of these cellular immunotherapies and lets us know what markers we should be looking for in patients' cells. "It also opens the door to producing cellular immunotherapies using healthy donor immune cells that contain those gene signatures."



Queensland's Deputy Premier and Minister for Health, Steven Miles, has welcomed the promising results. "Brain cancers are usually aggressive and have poor survival outcomes, so any new treatment that prolongs patients' lives is very welcome," Mr Miles said. "It is great to see Queensland's medical research institute working at the global forefront of research into immunotherapy."

As a next step, the team hopes to conduct another clinical trial combining the cellular immunotherapies with other forms of immunotherapy. The cellular immunotherapies were produced at QIMR Berghofer's specialist cell manufacturing facility, Q-Gen Cell Therapeutics.

The trial was funded by the National Health and Medical Research Council (NHMRC) and philanthropic donors.



Horizon Bank at Albion Park Supports the BTAA

After losing a colleague to a brain tumour, the staff at the Horizon Bank in Albion Park near Wollongong have raised funds to support the BTAA. In 2017 they held a movie night fund raiser and were able to donate \$1384 to help support our organisations 1800 Support Line.

This year they raised a further \$1000 after conducting a well-attended high tea. Jo-Ellen, Michelle, Melanie and Hazel report, "It was a lovely afternoon filled with yummy food, games, raffles, music and lots of fun!"

Great work and thanks to all of the team at the Horizon Bank in Albion Park. Hopefully some of our Wollongong members will be able to drop in and give their personal thanks.





Childhood brain cancer survivor program secures \$1.9m grant

UNSW Sydney researchers are leading a program to help childhood brain cancer survivors improve the quality of their life.

UNSW Professor Claire Wakefield and her team at UNSW are leading a program to help childhood brain cancer survivors improve their confidence, manage their health and improve their quality of life. The trial to roll out and test the effectiveness of the program – called Re-engage – was launched in August.

Funded by a \$1.9 million grant from the Government's Australian Brain Cancer Mission, part of the Medical Research Future Fund (MRFF), the program is part of a \$9.9 million investment in brain cancer survivorship research announced by the Australian Government.

"Over 90 per cent of childhood brain cancer survivors have health problems after they finish cancer treatment, yet most Australian survivors are not receiving the follow-up care they need to manage these problems," Prof. Wakefield said.

"Re-engage is a distance-delivered program that offers survivors two nurse consultations and careful case review by an expert team. This means that survivors can access support no matter where they live. Our nurses create a care package for survivors which includes a summary of their care needs, a letter for their GP, and education about healthy lifestyles."

Prof. Wakefield said the pilot study of Re-engage confirmed that the program significantly improved survivors' confidence to manage their health. The pilot

study was supported by The Kids' Cancer Project, Cancer Council NSW, and Kids Cancer Alliance.

The findings of the pilot were published last week in the *Journal of the National Comprehensive Cancer Network*. Six months post-program, all survivors said Re-engage was beneficial, with 84 per cent reporting satisfaction with their care and 73 per cent saying it improved confidence to manage their health.

The next step in the research project – the Re-engage trial – is significantly larger and includes childhood brain cancer survivors treated at Sydney Children's Hospital, Randwick, The Children's Hospital at Westmead and Perth Children's Hospital. The trial will evaluate the impact of Re-engage on survivors' quality of life and their ability to self-manage their survivorship care. The trial also focusses on developing and testing a detailed implementation strategy so that Re-engage can be rapidly rolled out nationwide.

Carole Boreham's daughter, Heather, is a childhood brain cancer survivor. Heather received care at the Sydney Children's Hospital in 1991 and her family helped design the Re-engage trial. "This journey doesn't end when you leave the hospital, far from it! It is only the beginning of what we hope to be a very long-life journey. Any ongoing support is invaluable in our efforts to keep our children healthy, productive, valued and appreciated throughout their lives," Carole said.



Professor Claire Wakefield. Photo: Rebecca Collins.

“We are very grateful for all the care Heather has. We are aware that children with the same diagnosis don’t always share the same journeys so a ‘one size fits all’ approach is not appropriate. More research into survivorship is required in order to bring about the best outcomes for our brain tumour survivors.”

Professor Richard Cohn, Director of the Survivorship Program in the Kids Cancer Centre at Sydney Children’s Hospital said: “Re-engage aims to give patients and their primary health care providers the essential information required for informed and supported cancer-directed, comprehensive follow-up care.

“To overcome barriers to hospital attendance and overcome the tyranny of distance for rural and remote survivors, advances in technology are used to facilitate access to the advice of a multidisciplinary team and to encourage as much care as possible close to home.”

A media release by The Hon Greg Hunt MP, Minister for Health, said the government was supporting new approaches and technologies to improve communications between brain cancer survivors, their families, carers and health care professionals. “The Australian Brain Cancer Mission aims to double the survival rates and improve the quality of life of people living with brain cancer over the decade to 2027, with the longer term aim of defeating brain cancer,” it stated.

To learn more about the Re-engage program, or to get involved, please visit:
<https://www.behaviouralsciencesunit.org/engage.html>

Quilts Donated To Raise BTAA Funds

The amazing women at Rosewood Craft and Quilters (RCQ) meet weekly to create beautiful quilts as well as other crafts.

Their beautiful work is either made for themselves or loved ones. A lot of ladies donate their completed pieces to be given to charities to support their fundraising. This generosity - imagine the hours that go into making a lovely quilt, is heart-warming and can make a big difference to organisations like BTAA. We have been very lucky to be given six beautiful quilts by the wonderful women at RCQ.

BTAA was chosen because RCQ member Wendy Quinton and her family, lost their daughter and sister, Sam to brain cancer three years ago when Sam was only 36. Sam had been diagnosed with brain cancer ten years earlier. Wendy particularly likes making quilts for children and a number of these are treasured by the children of friends Sam and her family made during her time battling brain cancer.

BTAA sends it’s thanks to the skilful and generous quilters at RCQ. We are privileged and delighted to receive your beautiful work. The much needed funds will be used to support the operation of the BTAA’s 24hr Support Line, our information packs for newly diagnosed patients and or support groups and forums.

To get your tickets in this fantastic raffle go to the BTAA webpage:
<https://btaa.org.au>

or direct to :
<https://www.rafflelink.com.au/btaa2020>

If ticket purchases have any difficulty contact the BTAA on 1800 857 221



Brain Tumour Society Singapore Visits Sydney Support Group and BTAA Links In With Asia Pacific Brain Tumour Alliance

Melissa Lim established the Brain Tumour Society Singapore in 2014 after her own battle with brain tumours. Melissa was inspired on a recent visit to the BTAA Sydney Support Group, at the Chris O'Brien Life House in November 2019, after seeing the informative and caring support group in action.

Melissa was a caregiver to her late mother who had brain cancer and became a patient herself when she was diagnosed with Acoustic Neuroma in 2003. On both occasions, she found the brain tumour journey to be an extremely lonely and challenging one, like a roller coaster ride where her family had to face the steepest drop alone, given the absence of peer support groups in Singapore at that time.

What helped her immensely in her own recovery from facial palsy and double-vision in the aftermath of her 16 hours long brain tumour surgery was the encouraging stories that the ward nurses told her. Melissa writes, "My heart was filled with hope when I heard how others before me had recovered fully. Along with it, my resolve to regain my independence grew. Initially, I lamented the fact that I had to battle with brain tumour not once, but twice. However, when I pondered about the deeper meaning of these turn of events in my life, I realised that I could bring good out of my suffering by sharing my experience and knowledge with others who are fighting this disease."

Upon Melissa's recovery, she sought out a patient support group and stumbled upon an informal one. In 2014, Melissa decided to register this group officially as the Brain Tumour Society (Singapore), also known as BTSS. Now 5 years after it's establishment, it is now a registered charity in Singapore serving a community of 150 patients and caregivers. The BTSS has financial grants and services catering to different segments of it's community: children, adults, homebound, financially challenged. It also has a medical advisory board comprising neurosurgeons, neuro radiologists and oncologists who support BTSS by talking educational talks. In addition, many of them are working closely with the BTSS to explore and bring in new treatments for Singapore brain tumour patients, such as Tumour Treating Fields (TTF). The BTSS recently managed to secure TTF for a GBM patient in February just before Singapore's circuit breaker measures and are glad that the patient is doing well.

BTSS also undertakes awareness building for the little-known brain tumour cause in Singapore, and we do this through the biennial Brainy Car Rally which

features 30 Lamborghinis ferrying our paediatric patients in a thunderous and amazing joyride in the city area. It had planned for our fifth Brainy Car Rally in November, but will have to schedule this to March 2021 in view of the coronavirus crisis.

In the course of managing BTSS, Melissa often comes across emails from patients and caregivers in the APAC region seeking advice and practical assistance for their brain tumour patients. Unfortunately, the BTSS constitution did not allow them to do more than offering peer support online. While at the International Brain Tumour Alliance Summit in Oct 2019, Melissa met patient leaders from APAC and thought that perhaps, we can join forces to form an alliance to help these patients. Melissa's associates from India, China, Hong Kong, Japan, Australia and New Zealand had a couple of informal meetings over dinner and at tea breaks and decided that they would keep in touch when we returned to our countries.

We did just that! With the support of the Chair of International Brain Tumour Alliance, Kathy Oliver, we formed the Asia Pacific Brain Tumour Alliance (APBTA) and we have since had two ZOOM meetings in 2020.

In the first APBTA meeting, we discussed how COVID-19 has changed the landscape for brain tumour patients and pooled together ideas and resources to help patients around the world. In the second meeting, members shared the stage of their lockdowns and also explore the development needs of different patients' groups in respective countries. In response, BTSS invited Catherine to join our e-Forum on Healthcare for Brain Tumour Patients during the COVID-19 Crisis while Dr Nitin Gard from India also participated in our ZOOM support group.



Melissa with members of the Sydney Support Group

Robert Connor Dawes Fund Fights to Save Lives

Connor Dawes was an ebullient and spirited 18-year-old whose life was cut short by a brain tumour.

Athletic and academic, Connor was diagnosed with an Ependymoma in 2011. After a 16-month battle, which included major surgery, intense radiotherapy and chemotherapy that resulted in loss of movement to his right side, poor vision and severe memory loss, he died in 2013.

Connor's mother, Liz, says his spirit endured even as his bodily functions deteriorated.

"He fought the good fight, the best fight, with dignity, courage and humour that belied his years," Liz says.

After Connor's death, his family created the RCD (Robert Connor Dawes) Fund to honour his memory and raise money for both research and the types of care that kept him at home until his death - such as musical therapy, yoga and an in-house nurse - for young people battling brain cancer who otherwise could not afford it.

"He never complained the whole time he was sick; cancer is terrible but he handled it in such a noble way," Liz says.

"He only had 18 years but this way, through the charity, he lives on. For me it is a natural response to what has happened, this is how I'm still being his mum."

Brain cancer is the most fatal and most common of all childhood cancers. Clinical treatments help just 50 per cent of children but leave 90 per cent with lifelong physical and mental impairments, yet funding for research is limited.

According to Cancer Council Australia statistics, 1680 brain cancers were diagnosed in 2010. In 2011, there were 1272 brain cancer-related deaths.

About 1400 malignant brain tumours are diagnosed in Australia each year, about 100 in children. Data about benign brain and spinal cord tumours is not collected but Cancer Council Australia estimates 2000 people, including children, are affected each year.



It is not known what causes brain tumours and there are no proven measures to prevent them.

This year, the RCD Fund held its 8th annual Connor's Run, an 18.8-kilometre fun run. In 2019, over 5000 participants raised more than \$1.2 million, the biggest run yet. In total the past seven Connor's runs have raised \$4.6 million for paediatric brain cancer.

"Researchers are on the verge of a breakthrough, they just need support," Liz says.

They hope that a collective voice will put brain tumour matters on the agenda for more research and funding so that the killer can be eradicated.

"I often told Connor that his brain was a gift and only he could decide if he wanted to share his gift for good with the world," Liz says.

"He never really got the chance but now we can do it for him."

Caring for the Carer: Development and pilot testing of an online intervention for family carers of high grade glioma patients

Four major Australian universities and a team of researchers (Prof Anna Nowak, Associate Prof Georgia Halkett, Dr Helen Haydon and Prof Thea Blackler) are developing an online intervention aimed at addressing the unmet needs of carers of people with high grade glioma. They need to pilot the intervention by recruiting carers who are willing to use the website and complete some surveys and an interview. If you would like to participate, read the flyer on the back page of this magazine.

Advocacy Organizations and Professional Societies from Across the Globe Unite on Brain Tumour Patients' Charter of Rights

Seventy-five brain tumour organizations from around the world have endorsed the new *Brain Tumour Patients' Charter of Rights*, a document intended to help initiate positive change in the care of people diagnosed with brain and central nervous system tumours. The Charter provides a framework for the reduction of inequalities in care and the achievement of policy objectives aimed at improving healthcare systems and communications. It can also be used by individual patients to underpin particular aspects of their care. Ultimately, the goal of *The Brain Tumour Patients' Charter of Rights* is to achieve the best possible health and quality of life for adults, children and adolescents living with brain tumors by encouraging and supporting quality standards, policies, and practices.

The Charter sets out the rights to which all brain tumour patients and caregivers should be entitled no matter where they live in the world.

"*The Brain Tumour Patients' Charter of Rights* has worldwide relevance," said Kathy Oliver, Chair of the International Brain Tumour Alliance (IBTA) and one of the members of the Charter drafting group. "We're excited that so many patient organizations and professional societies are supporting the Charter and we hope it will prompt productive discussion and debate and bring about positive change where necessary. The *Charter* is the result of a truly global collaborative process to help people who are diagnosed with this devastating disease, and those who care for them and treat them."

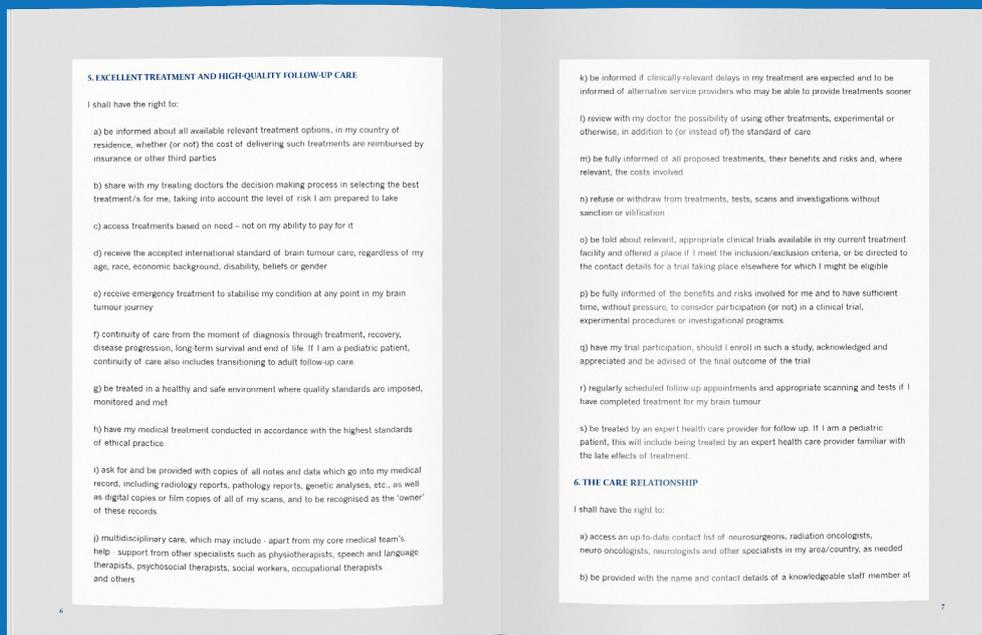
THE BRAIN TUMOUR PATIENTS' CHARTER OF RIGHTS

The *Charter* enumerates ten fundamental categories of "rights" for brain tumour patients that every country should strive to deliver:

1. Acknowledgment and Respect
2. Appropriate Investigation of Signs and Symptoms
3. A Clear, Comprehensive, Integrated Diagnosis
4. Appropriate Support
5. Excellent Treatment and High-Quality Follow-Up Care
6. The Care Relationship
7. Supportive/Palliative Care
8. Rehabilitation and Wellbeing
9. Medical Information and Privacy
10. Appropriate End-of-Life Options and Care

Within each category, specific policies, practices, and standards – a number of which will be aspirational in some countries – are defined.

The Brain Tumour Patients' Charter of Rights was developed through a multi-stakeholder and iterative process and is a "living document", subject to annual review.



Brain Tumour World View

- There are over 100 histologically distinct types of primary brain and central nervous system (CNS) tumours, each with its own spectrum of clinical presentations, treatments, and outcomes.
- Brain and CNS tumours can affect anyone of any age – from very young babies, children and adolescents to young adults, older adults and the elderly.
- Brain and CNS tumours are responsible for substantial symptoms, side effects and mortality worldwide.
- The worldwide incidence rate of primary malignant brain and other CNS tumours in 2018, age-adjusted using the world standard population, was 3.5 per 100,000. Incidence rates by sex were 3.9 per 100,000 in males and 3.1 per 100,000 in females. This represented an estimated 162,534 males and 134,317 females who were diagnosed worldwide with a primary malignant brain tumour in 2018, an overall total of 296,851 individuals.

- In the United States, brain tumours kill more children under 15 years than any other cancer.
- In 2016, malignant brain and CNS tumours were responsible for 227,000 deaths globally with an age-standardised death rate of 3.24 per 100,000 person-years.

The BTAA welcomes the introduction of *The Brain Tumour Patient's Charter of Rights*, and commends all of the worldwide organisations who have contributed to this historic document.

To view the full *Charter* go to the BTAA website at : <https://btaa.org.au/resources-support/living-brain-tumours>

Or to the IBTA website at: <https://theibta.org/ibta-news/advocacy-organizations-and-professional-societies-from-across-the-globe-unite-on-brain-tumour-patients-charter-of-rights/>



Rehabilitation Hospital Helps Father With Terminal Brain Cancer Walk Daughter Down The Aisle

As Canberra Support Group member, Graham Coddington's daughter's wedding day approached, he feared he would not be able to walk her down the aisle. Graham was a popular and regularly attending member of the BTAA Canberra Support Group after being diagnosed with a GBM including three operations and extensive treatment.

As a result of treatment Graham struggled with speech and movement. However there proved to be no greater motivator than being there for his daughter on her wedding day, and leaving her a special memory to cherish forever but thanks to his work with his specialists and team at the University of Canberra Rehabilitation Hospital, he was able to.

"It was an incredible motivator and a very, very special day for us both," Mr Coddington said.

"I knew how important it was for my daughter to have me 'take her down the aisle'.

"Until the physiotherapy team at UCH came to my assistance with specific exercises to help me maintain the strength and ability to walk, I felt strongly and very worried that I would not be able to achieve it.

Mr Coddington said it was an incredibly important moment for him and his tight-knit family.

He was even able to give a speech at the wedding, thanks to hours of work with the hospital's speech pathology team.

"I knew it meant the most to her for me to be there and for her to have the memory of that moment," he said.

"The speech pathologist, Lilly, assisted by preparing charts to help with recollection of words that were difficult to say due to my aphasia.

"She also then spent many hours helping me construct my speech for my daughter's upcoming wedding, making it simple for me to construct, keep simple and timely, read and guided me in vocalisation techniques.

"I was ecstatic the way it came together, if I do say so myself I spoke excellently!"

He is one of thousands of patients to be treated at the purpose built rehabilitation University of Canberra Hospital since it opened two years ago.

BOOK REVIEW

The Power of Your Sub-conscious Mind, by Dr Joseph Murphy

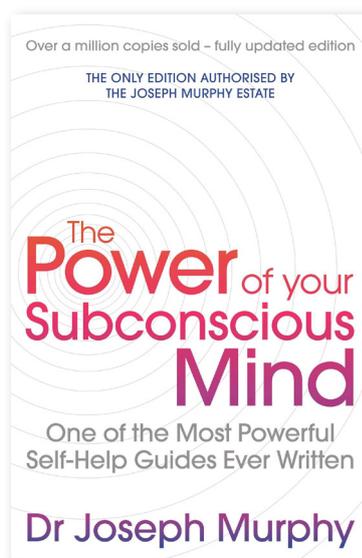
I came upon this book almost by accident, in the pile of half price books at my local QBD bookshop. It caught my eye, so it was meant to be! This book has changed my life and outlooks on a few areas (including cancer treatment) and I hope, and know, it can do the same for you.

I don't think it is an understatement to say that this book, and the concepts and ideas presented may change your life, brain tumor or not! I can fully understand why there have been over a million copies sold. The reach of this book is likely to have gone far further than just those 1 million copies. The copy of book that I got is the fully updated edition, that aligns some of the bible passages to the New English version, also there is a dot point summary of key concepts at end of each chapter emphasizing your takeaways as you read (I found this super handy to assist learning through Chemo Fog!).

Now as I have mentioned the bible you need to know that this book appeals to all folks who believe in many religions and philosophies. Murphy is excellent in his bridging the gap across philosophy and religion. More on that soon. But please (I am happy to beg) read this book. It is a game changer it is not a Christian only book. The critical piece of this book is to hold an open mind as you commence your read. This note is given to the reader in the preface as well.

Enough of the waffling on, the underpinning concept of this book is that you have two components of your head, that is the conscious and sub-conscious mind. While that concept most folks understand, what is not more widely considered is that means you have an awake component to your mind (conscious) and a part that keeps you running while you rest relax and sleep (sub-conscious). Which throws on it's head the idea that when you sleep you get rested because you switch off! What keeps you running 24/7/365 is your mind and small powerhouse computer known as your sub-conscious.

The sub-conscious keeps you breathing, manages stomach processes, keeps organs running, and is the interface to the conscious that does close down (to an extent) while we sleep. The sub-conscious mind is referred to as the treasure house within. And further that you can use your conscious mind to plant thoughts and goals and ideas of your future into your sub-conscious to work on 24/7 for you. This is true of many areas, from health to relationships, happiness, wealth, human relations, fears and many other areas.



As each chapter develops, Murphy provides examples of individuals that he ministered (or coached), through various areas and how they developed prayers or meditations to use throughout each day. Which is why it doesn't matter your faith. Because due to his background he relates to all readers using meditations or prayers, I would even say positive affirmations, to place in your sub-conscious mind to allow it to work away through the whole day, including sleep.

Murphy is not the only person to consider mind power as an augmentation to healing (otherwise known as self-healing), but he was certainly in the modern era a first of type in the western world, following the development of science based medicinal cures.

This book is worth your time. If you had the time to read only a couple of self help style books in your life, this needs to be on that list. To round this review out I will give you a small insight into how it changed my day. Each day now I regularly say to myself and even meditate on these affirmations:

- I am fit, healthy and well.
- I remain relaxed and calm in all situations.
- I live in peace and harmony with my environment.
- I release my sub-conscious mind to regenerate, rejuvenate and rebuild every cell and fibre in my body to the 100% perfection that it can.

I know with a prognosis that I was given some of these may seem none to smart. But hope is our internal flame, and our bodies and minds are more powerful than doctors give them credit for. I will keep my flame fanned and glowing for some time yet.

Stay well, and hug your fam,

Nathan

www.bu11itt.wordpress.com

Book Reviewer: Nathan Draper

Hi all, I am Nathan and have linked up with my local BTAA group in Canberra after receiving diagnosis of GBM grade IV in October of 2019, at the age of 49. My treatment to date has been Surgery, Radiation Therapy, and Chemotherapy (two rounds left). I am an Aeronautical Engineer in the Air Force and married to Christine with two boys (19 and 15). I have been reading a few interesting books recently, and I hope to be able to share a few more of my thoughts on others in the future.

Can you help to test an online program that supports people caring for someone with a brain tumour?



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

1800 857 221

Caring for the Carer: Testing an Online Program to Support Carers of People with Brain Tumours

We are testing an online computer program (like a website) that is designed to provide practical reliable information and support to people who care for an adult with a brain tumour.

Can you help us?

If you fit the following criteria would really appreciate your help in testing our online support program:

- Are aged 18 years old or above;
- Are looking after an adult with a high grade glioma (Grade 3 or 4; e.g. glioblastoma, anaplastic astrocytoma, anaplastic oligodendroglioma, anaplastic ependymoma);
- Have regular access to the internet;
- Have an email account or are willing to get one;
- Have a computer, tablet computer (e.g. iPad) or mobile device you can access the internet on

What does it involve?

You will be shown how to access an online program. The program is like a website with a range of topics that are designed to help someone looking after a person with a brain tumour. You will be asked to do an online questionnaire and then given access to the online program so that you can use the program as much as you wish over a four week period. After the four weeks, we will ask you to complete another questionnaire and then ask for your feedback about the program (via a telephone or in person interview). After the study, a few people will be invited to contribute to a video discussing how to cope with the stress of caring for someone with a brain tumour.

HREC Approval: 2018002631

If you are interested in receiving further information on this study, please contact:

Dr Helen Haydon: 07 3176 4462
h.haydon@uq.edu.au



SPREAD THE WORD!

Please LIKE, ADD, SHARE, COMMENT and SPREAD the word via our Twitter, Facebook and LinkedIn accounts! This not only helps our voice to be heard but also gives you a chance to reach out, interact and communicate with BTAA and the wider brain tumour community!

1800 857 221
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Brain Tumour Alliance Australia



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Search 'BTAA' on YouTube

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