



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

1800 857 221

OCTOBER 2023

BTAA.ORG.AU



DARREN HICKEY

Brain Tumour

Marathon

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5 STRATEGIES
FOR COPING**

**ABCF - SHINING A
LIGHT ON THE FIGHT
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**BRAIN TUMOURS
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**THE BRAIN CANCER
GROUP - CARE IS AT
OUR CORE, CURE IS
OUR GOAL.**

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15th COGNO ANNUAL SCIENTIFIC MEETING
SYDNEY, 8th - 10th October 2023

15TH COGNO ANNUAL SCIENTIFIC MEETING

Patient Education and Information Forum

Sunday 8th October 2023
Hilton Sydney 488 George Street

Facilitated by Marina Kastelan
Neuro Oncology Nurse Practitioner, The Brain Cancer Group

SPEAKERS



Prof. Martin Taphoorn MD PhD
Leiden University



Dr Ben Kong
BSc(Hons), MBBS, PhD, FRACPD
Medical Oncologist – Prince of Wales Hospital,
NHMRC Clinical Trials Centre, UNSW



Prof. Matthew D. Dun PhD
The University of Newcastle (UON)



Dr Sarah Bray
Project Manager - Brain Tumours Online at
University of Melbourne



Peter Ramstadius
Website Coordinator and Helpline -
Brain Tumour Alliance Australia (BTAA)



David Hewitt
Manager School Relations & Seeking Equanimity -
Mindful Meditation Australia



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LETTER FROM THE CHAIR

Welcome to our October 2023 Brain Tumour Alliance Australia Magazine.

The BTAA aims to support, inform, represent, and connect all members of the brain tumour community including patients, carers, family members as well as medical professionals and other brain tumour organisations.

Following the Covid years, some of our face to face support groups suffered from declining numbers, but recently there has been a pleasing increase in attendance. This, combined with more patients joining online, means that more patients than ever are able to access the benefits of our support groups. A comprehensive list of support groups is available on the BTAA website.

Our 24/7 telephone support line has continued to remain an important first point of contact for newly diagnosed patients and carers.

Our patient support forums have also been very successful. Two forums have been conducted in conjunction with The Brain Cancer Group in Sydney and a further forum will be held before the COGNO Annual Scientific meeting. These forums have been recorded and can be viewed online from our website.

The E-news and magazine provide regular information on brain tumour events, patient stories and new programs and research. Circulation remains at more the 2000 copies each edition. Many organisations have abandoned hard copy publications, but we still believe these to be an effective manner of communication. Our website contains comprehensive information and links to resources and organisations across the country. Our multilingual resources in ten languages are also unique.

The formation of the Australian Brain Tumour Collaborative Group, which was led by the BTAA, has now been joined by all major Australian brain tumour support groups. The formation of this peak body, will not only connect the many fantastic brain tumour groups across Australia, it will form a united voice to represent brain tumour patients, carers and their families. As the Federal governments review of National Disability Insurance Scheme eligibility, and the Medical Technology Assessment are underway currently, the collaborative group will have an important role to play in representing patients across the nation.

The BTAA is an entirely volunteer organisation. Our support groups, 24/7 support line, publications, website, events are all run entirely by a team of dedicated volunteers. The organisation is run on a shoestring, and does not actively fundraise, and depends on the many generous donations that we receive. Thank you to all who have donated or raised funds on our behalf.

THANKS TO

| | |
|----------------------|--------|
| Jenny Firth | \$2000 |
| Shane (from Ripcurl) | \$4500 |
| Darren Hickey | \$4600 |

All those who donated at the funerals of:

Harry Parsons & Denis Strangman

Craig Cardinal
Chair



Craig's wife, Berlinda, was diagnosed with high grade brain cancer in October 2015. Craig joined BTAA after years of experiencing and witnessing the struggles of brain tumours survivors, families and carers whilst navigating services and supports in Australia.

Craig spent close to 30 years with defence and served in the Royal Australian Air Force, Royal Australian Navy and as a public servant with the Department of Defence. Craig also served with the Australian Customs and Border Protection Service and has consulted and contracted to industry, state and Commonwealth governments.

Craig is passionate about contributing to the improvement of services and supports for brain tumour sufferers and families.

Head to the Hill this November

Diane Dunn

In 2020 an idea was formed by BTAA's committee, that we should attempt to hold an annual event of some sort to raise awareness for brain tumour patients, and their families. Modelled on the very successful event held in Washington DC, and organised by the National Brain Tumour Society in the USA, we decided that we too should hold the event in our capital with a view to bringing the issues directly to the door of Government.

At the NBTS's event - which takes place in May (to coincide with Brain Tumour Awareness Month) participants are encouraged to share their personal stories and raise awareness of critical issues facing the brain tumour community. Head to the Hill in Washington began in 2011 with 31 advocates attending the event. It has since grown year upon year with hundreds now attending.

We intend to do the same at our event "Head to the Hill" which will provide an opportunity for the brain tumour community to have their voices heard and to motivate those who make policies and determine funding to prioritise our needs.

Critical to the success of such an event is the support of politicians, and so we determined that we should approach Government directly, to outline our plans and seek support to stage "Head to the Hill".

After many attempts thwarted by Covid, the BTAA's Chair and Secretary finally travelled to Canberra on the 21st June 2023, to meet with the Health Minister Mark Butler and Senator Catryna Bilyk, who understands first-hand the impact a brain tumour diagnosis can have on your health, both physical and mental.

Both Minister Butler and Senator Bilyk were very receptive and open, and listened to our pitch for an annual event modelled on the NBTS's event in Washington. They both indicated they would support BTAA in any way they could to ensure this event became a reality.

Minister Butler in particular, was impressed by the progress made by BTAA towards initiating and successfully forming a national collaborative of brain tumour organisations (The Australian Brain Tumour Collaborative Group). This collaboration in part came about as a result of previous conversations we had undertaken with Minister Butler when he was the Opposition Health Minister, and he indicated that it was far preferable for politicians to be approached by a representative group rather than individuals or single organisations.



Photo: Federal Minister for Health and Aged Care, Mark Butler, Diane Dunn, Craig Cardinal, Senator Catryna Bilyk.

It was somewhat surreal to be escorted through the corridors of Parliament House, the very same corridors which are regularly featured in news reports.

We were grateful for the opportunity to have our ideas heard, and in particular to Senator Bilyk who afterwards talked with us over coffee. Her enthusiasm for the event was evident and genuine and filled us with hope that this event could now become a reality!!

Minister Butler suggested that like the event in Washington, we should encourage our community to make contact with their own MP's and ensure they know about their constituents who are living with, or care for somebody, with a brain tumour. They should be advised of issues which affect YOU and your family so that in turn those issues might become priorities for the Government.

So stay tuned for an announcement around dates and times in the very near future!

As an organisation we are passionate about empowering the brain tumour community to advocate for change and we believe this event will provide that opportunity. It will also provide a much needed opportunity for making connections with other patients, carers and families.

It was only possible for me to travel to Canberra with the support of my partner. Due to some deficits I now suffer as a result of my own brain tumour, I could not have navigated this trip alone. It is imperative to highlight the amount of support that stands behind brain tumour patients.

COVER STORY

Darren's Story

In early November last year (2022), I developed a splitting headache, seemingly out of nowhere. After treating it as a migraine for nearly a week, and with no relief, I finally went to see my GP. He was extremely thorough and provided me with a form to get a CT scan, if the script for stronger painkillers did not work.

Two days later I was being told to take myself to the Emergency Department by a very concerned radiologist as there was a 5.5 cm mass detected, but more importantly it was bleeding. I spent the next two weeks at St Vincent's Hospital in Melbourne, under the care of some of the best neurosurgeons and nurses in the country. The tumour was successfully removed.



I was then sent home to recover, before returning to receive the pathology results that would change my life forever. The results showed that the tumour was a Glioblastoma, a high grade brain cancer. Shortly after, I began chemotherapy alongside radiation therapy. These treatments continued into the new year. High grade Glioblastomas bring with them a prognosis of 1-2 years, however, I was told that a couple of molecular markers within the DNA of my tumour, meant that mine should respond better to the chemotherapy treatment than most other GBMs.

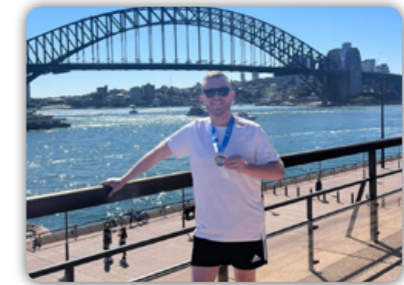
It was at that time that I was inspired by the story of a Canadian man who had received an identical diagnosis at 29, the same age as me. He is a long-term survivor and ran his first marathon one year post diagnosis, and that is why I am going to run the Sydney marathon myself this year. To prove that I can do it too, and hopefully help raise some funds and awareness for the great work that the Brain Tumour Alliance Australia does. The BTAA is a volunteer run organisation that provides support, tools, resources, and care to brain cancer patients and their families.

I hope my story inspires you to make a donation to the BTAA, however great or small, so that they can continue to provide invaluable support, and raise awareness for those that find themselves with a frightening and uncertain future with brain cancer.

Thank you, I really appreciate your support.

Darren Hickey

Darren Hickey



Give Now

A FANTASTIC ACHIEVEMENT! CONGRATULATIONS DARREN!

\$6,071

Raised of \$10,000

For **Brain Tumour Alliance Australia**

Support Brain Tumour Alliance Australia in the Sydney Marathon 2023



The 2023 Sydney Marathon is an iconic event with a spectacular course that includes a run over the Sydney Harbour Bridge and a finish at the Opera House. The festival will be held on September 17, 2023 and features the Sydney Marathon, Sydney Marathon 21km, Sydney Marathon 10km and the Sydney Marathon Family Fun Run 3.5km - so there is something for everyone. 40,000 runners are expected to participate in 2023.

| Overview | Donations | Updates |
|----------|--|---------|
| | Daina Murray gave \$53.55 All the best Darren 😊 | |
| | Ma & Pa Gilpin gave \$105.75 We are super proud of you young man. Running a marathon is pretty gutsy. We'll be cheering you on! | |
| | Yan and Alina gave \$53.55 Well done Darren! Keep fighting Champion! | |
| | Kek gave \$53.55 Cancer has no shame, no compassion, no guilt, it doesn't discriminate nor care. It is our responsibility to step up, to support, to give, to care and to keep striving to beat the living shit out of this disease. We're with you all the way Daz and beyond xxxxx | |
| | Robyn gave \$1,055.00 Cancer has no shame, no compassion, no guilt, it doesn't discriminate nor care. It is our responsibility to step up, to support, to give, to care and to keep striving to beat the living shit out of this disease. We're with you all the way Daz and beyond xxxxx | |
| | Maureen gave \$105.75 A great cause, run strong Darren. | |
| | Sara gave \$53.55 Good luck Daz x | |
| | Michael gave \$53.55 So proud of you Darren - you're a legend! | |
| | Mummas gave \$527.5 So proud of your courage and determination. Love always xxxxxx | |

load more...

Scanxiety — 5 strategies for coping

By Kate Bown



Bel wakes in the middle of the night and cannot go back to sleep. Her twenty seven year old daughter was diagnosed with three brain tumours this year and there is a lot of stress and worry in their lives. “We have a big [pathology] result coming up and it’s really starting to weigh heavily,” Bel shared. “It’s like having a black cloud hanging over your head. Life has gone on hold.”

What is anxiety?

Anxiety is a normal response to danger. It is an ‘early warning alarm system’ that gets your body ready to fight, to take flight, or to freeze until the danger has passed, Dr Hodgkinson shared. While small levels of anxiety can be useful in our day to day lives, too much isn’t helpful. Some common symptoms of anxiety include increased heart rate and breathing, nausea, insomnia, irritability, difficult in concentrating, a low mood, and feelings of panic. Living with a brain tumour is one of the many things that may trigger anxiety.

It can be difficult to know whether symptoms are due to anxiety, the brain tumour, or treatment, which is why it is important to seek input from your medical team.

Bel is not alone. According to Dr Katharine Hodgkinson MAPS, a clinical psychologist with a special interest in oncology from the team at Headway Health, many people living with a brain tumour, along with their caregivers, experience worry and fear associated with medical tests such as MRI, CT, and PET scans.

What is ‘scanxiety’?

There are many different types of anxiety. Scan anxiety or ‘scanxiety’ is a word used to describe the anxiety that people feel in the time leading up to a scan, during the scan, and while waiting for results. While it is not a medical term, scanxiety is well known in brain tumour and cancer support groups, oncology and psychology practices.

“Anxiety about the loss of confidence in your health or loved one’s health and the constant waiting – waiting for doctors’ appointments, waiting for test results, waiting to see if the treatments have provided the hoped for responses – can be very stressful and unsettling,” Dr Hodgkinson said. Often the very first scan carries with it the trauma of a brain tumour diagnosis and future scans can bring back these memories.

Scanxiety can be especially challenging for people living with a low-grade brain tumour or if you’re younger, because you may have years of medical surveillance ahead of you. For some people, scanxiety can interfere with wellbeing and quality of life.



Scanxiety toolkit

The good news is there are tools that people can use to manage scanxiety and “the more you have in your kit, the better,” Dr Hodgkinson shared. There is no ‘right approach’. It is best to try a few approaches and find what works for you.

1. Awareness and Learning

Learning about anxiety and your own response to it can be helpful for people experiencing scanxiety. The first step is to notice when symptoms begin. Take note of any trends or triggers, then accept that it is normal and okay to feel anxious. It is important not to ‘fight’ your anxious feelings, scanxiety is predictable and expected, Gabriella Rudman, Clinical Psychologist Registrar at the Menzies Anxiety Centre, said.

Remind yourself that anxiety will pass. Then you can turn your attention to what you need to do to get through. A further step is to reflect on what you did that was helpful and what you could do differently next time. “With practice and time you will become more confident in your skills and learn how to manage the bumps as well,” Dr Hodgkinson said.

2. Scheduling and Preparation

Scanxiety is fueled by uncertainty and a loss of control. Switching your focus to things that you ‘can’ control may help to reduce scanxiety. Dr Hodgkinson suggests scheduling scans at times that suit you, where this is possible. Then making a plan for follow-up appointments. Include rituals and routines that help you — lunch with a friend the day before the scan, or watching a favourite movie while waiting for the results. It can be as detailed and loose as you would like it to be.

3. Self-care

Engaging in self-care activities before and after a medical test can give you more capacity to cope with scanxiety. This includes eating well, staying hydrated, getting enough sleep, and taking your medication. Exercising, such as walking with a friend, can be beneficial too, this is because it helps get rid of excess energy and manage mood and sleep. It can also help to focus your thoughts on the present and to make the most of the time you have with loved ones.

4. Relaxation and Mindfulness Techniques

Many people living with a brain tumour become preoccupied with ‘what ifs?’ and worst case scenarios when a medical scan is approaching. Learning strategies such as distraction, relaxation techniques, and mindfulness can help to reduce scanxiety.

Engaging in distractions

Drawing, painting, gaming, or even doing a puzzle with a friend are activities that redirect your attention and can help to pass the time while waiting for a scan or results. Dr Hodgkinson suggests taking ‘things to distract you’ to a scan or follow up appointment — a mobile phone, audio book, craft, a word puzzle, or a fidget toy. You can also try mind-games when you are required to be still — list players in your favourite AFL team or count ceiling tiles. Everybody is different so it is important to engage in activities that you enjoy.

Breathing exercises

Awareness of breath and relaxation breathing can be helpful during a medical scan. It switches on the parasympathetic nervous system and calms the brain down. Start by becoming aware of your breath, breath in for a count of four, breathe out for a count of 4, and hold for 4 counts, then repeat. You can try bringing awareness to another part of your body if breath is difficult or uncomfortable, such as squeezing your toes for a count of four.

Mindfulness

Mindfulness activities reduce psychological distress. According to Katherine Watson, a clinical psychologist MAPS at Positive Frame Psychology, mindfulness is simply noticing when your thoughts are going into the past or the future, and then bringing your attention back to the present. You can do this through either a formal meditation practice or mindfulness of everyday activities, for example washing up or brushing your teeth. Start by paying attention for two minutes to all of your five senses when cleaning your teeth — vision, hearing, touch, smell, and taste. Every time you get distracted, acknowledge it, and then just come back to your teeth. Over time you will improve your skills and reduce your anxiety.

Communication and Support

If you notice that your anxiety is prolonged and/or worsening you may wish to seek help. Communicate your concerns with your health care team. They will be able to refer you to a mental health professional who has experience in supporting people living with a brain tumour. Effective treatments are available. It is important to talk openly with the people around you. Sharing your experiences with other patients and survivors in a support group can also be beneficial.

MORE INFORMATION

www.beyondblue.org.au

www.cancer.org.au

www.headwayhealth.com.au

If this article has raised concerns for you, please call your local mental health team or contact Lifeline 13 11 14 or www.lifeline.org.au. If you feel in immediate danger please ring 000 or go to your local hospital.

Shining a Light on the Fight Against Brain Cancer: The Australian Brain Cancer Foundation's Remarkable Journey

By Milena Skepev

In the field of medical research, few challenges are as daunting as finding cures for brain cancer. Alarmingly, survival for brain cancer patients hasn't improved for over 35 years, so the fight to find a cure for this most challenging disease demands not only scientific dedication, but also sustained financial commitment and community support. With these pillars in place, we can work for advancements in diagnostics and treatments.

Brain cancer is an affliction of profound consequences, touching not only the individuals diagnosed but reverberating through their entire communities. Despite its devastating impact – claiming more young lives than any other disease in children and more adults under 40 than any other cancer – funding and focused attention for brain cancer research have often been overshadowed by research into other medical conditions. The Australian Brain Cancer Foundation (ABCF) recognizes this glaring disparity and aims to address the substantial gaps in funding and support for brain cancer research, with a particular focus on Canberra. Through determined efforts to bolster support for the dedicated medical research teams striving for a cure, the ABCF will not only underpin the development of life-saving therapies but also champion greater awareness of this devastating disease.

Established in 2023, the ABCF stands as an innovative not-for-profit organisation, founded from the commitment of Canberran Milena Skepev. As the first brain cancer research foundation in Canberra, the ABCF brings brain cancer research to the forefront of the local community's consciousness. Its mission is to raise awareness, advocating, and fundraising for brain cancer, benefiting patients, clinicians, and brain cancer researchers in the ACT region.

At its core, the ABCF seeks to support pioneering brain cancer research, showcasing Canberra's existing cadre of exceptional medical researchers, clinicians, and research facilities already engaged in the battle against brain cancer. By bolstering research fellowships and attracting the brightest minds to Canberra, the Foundation aspires to enhance the ACT's capabilities, ensuring that Canberra spearheads global innovation in brain cancer research – a critical step toward discovering the scientific breakthroughs



Mile Petrevski (Strategic Advisor), Tegan Elferkh (Public Officer), Milena Skepev (CEO/Founder, Director) and John Irvine (Director and Legal Advisor)

that can transform patient outcomes.

The Foundation's central mission is to bridge the current funding deficits and provide essential support for brain cancer research in the ACT. Moreover, the Foundation is steadfast in its commitment to promoting clinical care and resources to brain cancer patients and their families within the significantly neglected Canberra region.

One of the cornerstones of our funding strategy is to support brain cancer research fellowships, attracting the world's finest minds to the ACT. Through enduring partnerships with major Canberra institutions such as the Australian National University, the Canberra Hospital, and the University of Canberra, the Foundation seeks to nurture a local environment conducive to groundbreaking discoveries in brain cancer research.

The ABCF's origins are deeply intertwined with the Canberra community it serves, with its board comprising respected figures from the Canberra business community. Supporters such as John Irvine from Trinity Law, Nick Skepev from Zapari Group, Mile Petrevski, and Tegan Elferkh, from Maxim Chartered Accountants, played a key role in shaping the Foundation's legal and financial strategies. They not only provided essential initial funding but also committed to covering future administrative, legal, and accounting costs.



ABCF first board meeting with the Fundraising and Medical Advisory Committee

From Left: Dr. Peter Mews, Professor Leonie Quinn, Milena Skepev, Amanda Fintan, Colin McCulloch, John Irvine, Ursula Kohler, Dr. Hari Bandi, Dr. Kylie Jung, Naomi Mitchell, Dr. Ganes Pranavan.

Consequently, all Foundation funds will exclusively support causes recommended by the Board, guided by the Medical Advisory Committee's counsel. The Foundation's Board and Committees are firmly committed to upholding the highest ethical standards and maintaining transparency with donors and the public.

Likewise, the Foundation's Fundraising Committee features individuals deeply entrenched in Canberra's culture, such as Colin McCulloch, a brain cancer survivor who brings a wealth of experience in event management for major fundraising initiatives. Since his own diagnosis in 2011, he has been instrumental in raising over \$8 million for other brain cancer charities.

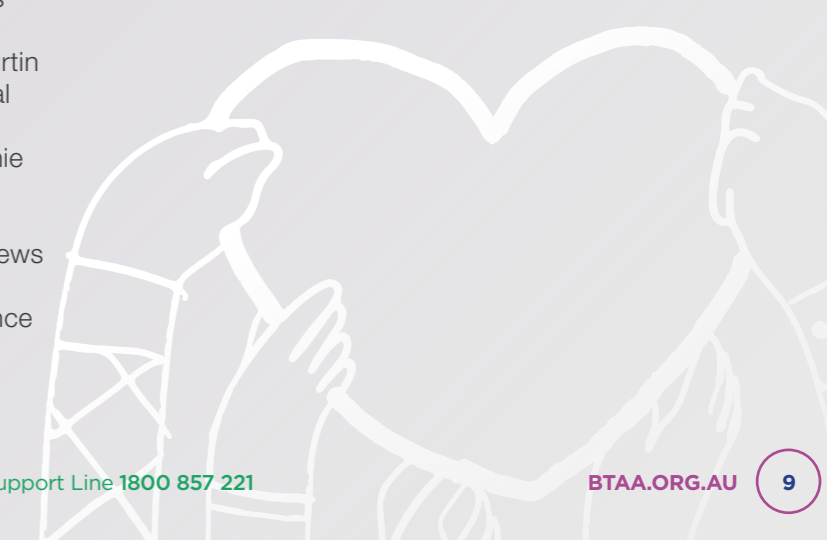
Amanda Fintan, the Foundation's Consumer and Engagement Representative, has served as Milena's philanthropic mentor for six years and also holds a position on the Advisory Committee. Her extensive experience in brain cancer patient advocacy and philanthropic initiatives focuses on Canberra. ABCF has now inherited Canberra's popular Brainstorm for a Cure gala ball that Amanda initiated. Through Amanda's extensive connections and experience in major event and philanthropic fundraising, our ambition is to raise significant funds to support our local community affected by brain cancer, while also funding innovative and globally recognised research right here in our Nation's Capital.

At the heart of the ABCF lies the Medical Advisory Committee, overseen by Professor Leonie Quinn, has assembled a team of deeply committed researchers and clinicians to form the Canberra Brain Cancer Collaborative, with affiliations spanning the John Curtin School of Medical Research, The Australian National University and The Canberra Hospital. The MAC includes research scientists such as Professor Leonie Quinn (ANU) and Naomi Mitchell (ANU); practising clinicians in the field of medical oncology including Dr. Ganes Pranavan; neurosurgery with Dr. Peter Mews and Dr. Hari Bandi; and radiation oncology led by Dr. Kylie Jung. Professor Quinn's extensive experience and expertise in brain cancer, have been central to establishing the Foundation's core objectives.

Notably, in August 2023, Professor Quinn led a successful grant application securing \$300,000 from the ACT Health Research Innovation Fund, enabling the establishment of Canberra's inaugural brain cancer Biobank. Professor Quinn's research capitalizes on more than \$20 million in cutting-edge cancer research infrastructure and technical expertise in high-throughput drug discovery established in the John Curtin School at ANU.

Brain cancer may be a formidable adversary, but the ABCF, an entity that emerges as a unifying force, bringing together medical experts, advocates, and individuals who share a common goal: to conquer brain cancer once and for all. As we stand at the crossroads of discovery, innovation, and compassion, the ABCF aims to lead the way, guiding us toward a future free from the shadow of brain cancer.

Milena is the CEO and Founder of the ABCF, is not only the leader of the organisation, but also a devoted mother of three. Milena has a diverse professional history that includes accounting, owning a hotel, coordinating weddings and functions, specialising in baby and children photography, cake decorating and commercial interior design. Her leadership and dedication to the cause, coupled with her ability to foster unity and shared purpose, have inspired others to rally behind the Foundation's mission.



No Use-By Date for Andrew

Andrew Hamilton - Brisbane Support Group member and GBM patient

I'm no different from a great many number of ordinary people. I planned. I had ambitions, a loving wife, kind and thoughtful daughter, a dog, comfortable home and great job as a manager at Sea World. I had very little to complain about, but I'm sure on occasion, I found something to grizzle about.

At the age of 40, I should have expected life to present me with some challenges, but I had no reason to suspect anything I can't handle.

Boy, did my outlook take a sharp turn on May 21, 2008, when the world stopped and I was told that I had a brain tumour. How did that happen? Surely it was just another one of my blinding migraines? No, this was different. I was muddling up my words. That's not like me. I speak for a living. Sure, I had been fairly busy in the last few weeks and not getting much sleep, but who isn't!

There was no getting around it. There it was in stark black and white. Confirmed by not only the CT, but the MRI. I have a brain tumour. A Glioblastoma Multiforme to be specific, or GBM to friend and foe alike. This is an especially nasty wee beastie, which is graded in nastiness from 1 to 4. 1 is bad, with 4 being the 'get your affairs in order' kind of nastiness. True to form and being the over achiever that I am, mine is a 4. Bummer!?!?

News could have been better, but the way I looked at it, that's what the statistics say. I've never been one to rely on statistics. They're just numbers. My neurosurgeon never talked in terms of a 'use-by-date' (my words, not hers), but all conversations were focused around what can be done.

From the outset and independent from each of other, my wife, Alison and I decided this... Anything we CAN DO, we will DO. Anything somebody more qualified than my CAN DO, they have my permission to DO. I have great confidence in the expertise of my medical team. Anything out of our control, isn't worth a moment's thought or effort.

My surgery journey started with a craniotomy to de-bulk a 5cm mass from the left parietal lobe, with good margins. Due to the fact the lesion was close to the speech and motor centres, there was a very real concern that I may suffer significant damage to these areas. Dr Sarah Olson prepared my wife, Alison for the very real possibility of my not being able to speak, as at this point, I was silent. Alison asked me how I was, the first thing I said to her was... One hen, two ducks, three squawking geese... Always the showman!

I continued to improve and prepared to start six weeks of radiotherapy combined with oral chemotherapy, Temozolomide. My radiation treatment consisted of being strapped onto the table, lying face down. Not the most comfortable way to spend 15 to 20 minutes. One hen, two ducks... I did my time and continued to grow stronger, but it wasn't all plain sailing. I revisited surgery, two more times over the three years since diagnosis. My Brain Tumour was now stable.



Andrew Hamilton

It stayed that way until round Christmas 2019, I was struck down by what I thought was a recurrence of my tumour. Off to hospital I went, for a CT then an MRI, where all was stable. After a few more tests and discussions with doctors, it was decided that I had S.M.A.R.T. Syndrome - an acronym for Stroke-like Migraine Attacks after Radiation Therapy. An uncommon delayed complication of cerebral radiation therapy. Very little is known about this and even less is available by way of treatment. But, it's real and it's a real pain - both physically and figuratively.

If bad things happen in threes, there's something wrong with my maths! It's the gift that keeps giving, on and on. If you've done the calculations, it's nearly 16 years since diagnosis. I still front up every three months for an MRI but the scans continue to be clear. Sure, I walk with a limp, occasionally muddle my words and struggle daily with my new rude 'F' word, FATIGUE!!

I'm otherwise, well. I've even completed the Bridge to Brisbane 5km walk/hobble a few times. I'm also taking medical cannabis, which is proving effective for me to manage residual pain.

I still have 3 monthly MRIs and so far, my scans continue to be clear. Smart Syndrome continues to presents a challenge, with pain and mobility issues. Statistics are one thing, but everyone is different. I've been through the mill, but I'm still here to talk about it. I'm one grateful anomaly!!

Life's adventure continues and I could not have made it this far without the support of my wife Alison, my daughter Alisa, family, friends and the medical professional at the PA. Every one's story is different. That's why there's no easy answer when faced with life's challenges. What I do know, is that a positive attitude and owning my situation, allow me to chip away at the bad stuff, to find the goodies underneath. It's well worth the effort.

Just keep breathing. Together, we can tackle the future, one step at a time.



Brain Tumours Online

Providing trusted information, peer support and tools for people affected by brain tumours in Australia, accessible online when and where you want it.

What is Brain Tumours Online?

Scan the QR code to watch short video.



Who is Brain Tumours Online?

Based on a decade of research and supported by the Australian government through the Medical Research Future Fund (MRFF), we have developed an Australian-first, online platform to provide brain tumour patients and their carers with streamlined evidence-based information and peer support.

Led by Prof Kate Drummond from the Royal Melbourne Hospital, our group includes a team of health care professionals (including neurosurgeons, oncologists, cancer care coordinators) and digital health researchers collaborating across multiple organisations and sites (including University of Melbourne, Peter MacCallum Cancer Centre, St Vincent's Hospital Melbourne and University Hospital Geelong), plus digital product designers (Two Bulls/DEPT), and people with lived experience of a brain tumour, as patients or carers.

Informed by co-design.

Before we started building, we interviewed patients, carers and health care professionals to find out their perspective on what really matters in a digital platform for people affected by brain tumours. We conducted a series of workshops and other co-design activities throughout the development of the prototype, impacting every aspect of the work - even the logo, name, colour palette and illustration style, as well as the content, of course!

What's on Brain Tumours Online?

Brain Tumours Online is a website that provides trusted information, peer support and tools for people affected by brain tumours in Australia, accessible online when and where you want it. Brain Tumours Online has three main 'pillars' - Learn, Connect, and Toolbox - to address different needs of people affected by brain tumours.

Better than 'Dr Google'... or trawling the internet trying to figure out which websites are trustworthy and relevant, the **Learn** pillar brings together trusted, evidence-based information in one place, categorised and signposted by our team to make it easier to find and filter the information you need.

The **Connect** pillar is the heart of the website, allowing patients, carers and health care professionals to connect with each other in a range of ways. There is a 'Stories' section where you can browse and read other people's personal stories and experiences, and

also share your own stories and wisdom. Having a brain tumour is an isolating experience, and traveling to in-person peer support groups or finding someone who understands and can share your experiences is difficult. Thus, we have created an online social media 'Community' forum that will provide a safe place for peers to find, connect and chat with others in a similar situation, no matter where you live in Australia. Our team will also be hosting online webinar events. Hear from health care professionals and brain tumour experts on topics that matter to you and take the opportunity to ask questions.

The **Toolbox** pillar will include evidence-based online tools and programs to help with symptom management and self-care that can be accessed when and where you want. Initially we will be testing a tool called SHUTi, an online cognitive behavioural therapy program for those experiencing trouble sleeping (insomnia).

Help us test and improve Brain Tumours Online!

While not yet publicly available, Brain Tumours Online has now been launched for an evaluation phase, and we are currently seeking up to 300 patients, 200 carers and 30 health care professionals across Australia to work with us to test and improve the site, and to demonstrate the value of the platform for future expansion and sustainability.

Through this evaluation we hope to learn what is working well, what can be improved, what more you would like to see added. We also hope to understand how you use the website, what features you find the most helpful, and whether the website has an impact on your quality of life, unmet needs or your use of health care services.

If you would like to be part of the evaluation of **Brain Tumours Online**, you can find out more information by visiting our website <https://braintumoursonline.org> and clicking '**Register for access**'.

If you meet the eligibility criteria for our study, you will be provided with a Participant Information and Consent form online, and a series of online surveys to complete. Once this is done, you will be sent a unique login and password to access Brain Tumours Online.

This study has ethics approval from the Royal Melbourne Hospital Human Research Ethics Committee (HREC/89522/MH-2022).

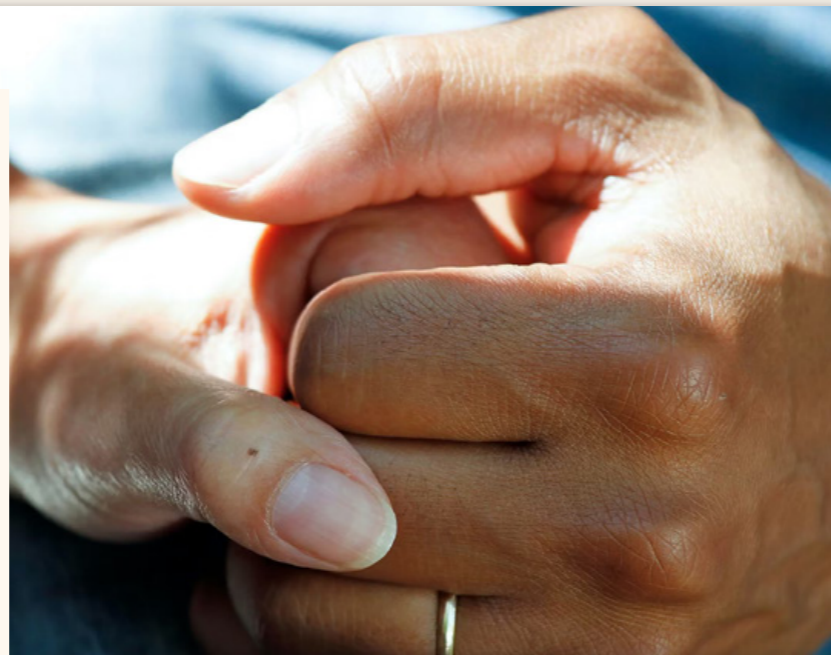




Care is at our core,
cure is our goal.

The Brain Cancer Group's aim is to provide a critical step, in ultimately providing individualised treatment, the right treatment, for the right patient, at the right time.

The Brain Cancer Group – care2cure, (formerly the Sydney Neuro-Oncology Group Ltd), was established on the Royal North Shore Hospital campus in Sydney, Australia in 2000 by neurosurgeons Dr Raymond Cook and Dr Michael Biggs, who were soon after joined by medical oncologist Dr Helen Wheeler. The TBCG tag line, care2cure, was chosen to reflect the commitment to the 3 Pillars of: **RESEARCH, EDUCATION** and **SUPPORT**.



Research

Laboratory research is performed in The Bill Walsh Translational Cancer Research Laboratory, Kolling Institute, University of Sydney, Royal North Shore Hospital campus. The research team works hand-in-hand with our clinicians, taking questions from the bedside to the bench and answers back to the bedside for improved patient care. This is called translational research.

The banking of brain tumours was started by our founding Neurosurgical Directors in 2001 with the vision of providing specimens to enable research to improve our understanding of brain cancer. This Bank is now incorporated into the Kolling Institute Tumour Bank (currently funded from other sources) and contains the largest collection of frozen brain tumours in Australia. Our recently appointed Biobank Officer will assist with the collation and matching of clinical data for the archived brain tumour specimens. The original vision of our Directors is now the reality, with specimens from this Bank contributing to major international studies that have advanced our understanding of these cancers and led to the development of new therapies.

The Brain Cancer Group Databank

The Brain Cancer Group Databank is one of TBCG's flagship programs and cements our commitment to the Research pillar. The TBCG Databank comprises three components: Tissue Biobank, Clinical Outcomes Database and the Brain Imaging Laboratory. The linkage of the three components will become a powerful tool for clinical decision-making and give patients more certainty of their futures. In practice, clinicians and researchers asking a question can access the brain tumour specimen, see how that influences the MRI appearance and then assess treatment outcomes.

Education

To help drive awareness amongst the healthcare community, we are focused on providing healthcare professionals with access to educational material relating to brain cancer. This increased awareness and education will improve patient outcomes. We also promote awareness amongst our patients, their families and the broader community.

Education Programs include:

- Partnering with Brain Tumour Alliance Australia (BTAA) to support and provide education to patients and carers;
- Hosting an inaugural Scientific Meeting in October 2019 in line with COGNO (Cooperative Trials Group for Neuro- Oncology). The content presented at the Scientific Meeting will contribute to the development of an online educational curriculum that will be available to healthcare professionals;
- A crossover between our Education and Support Pillars is our Collaborative Care Project, specifically our Neuro-oncology Nurses Network Meeting (NONN), at which we provide educational resources to future Clinical Care Co-ordinators;
- Presenting at medical and research conferences;
- Presenting at community events;
- We hold an annual awareness raising event at NSW Parliament House during May, Brain Cancer Action Month;
- Video library of webinars and educational events.

Support

To address the immediate and ongoing needs of brain cancer patients, TBCG fully funds the salary of a dedicated Nurse Practitioner. This provides a single, empathetic point of contact for patients, someone who can explain confusing treatment options and share information across the specialist team.

Our Nurse Practitioner forms part of the collaborative team that works across multiple neuro-oncology disciplines to provide tailored care that puts the patient's needs first. In addition to providing ongoing support to patients and families, the expert Nurse Practitioner is also helping lead a Collaborative Care Project to provide support and resources to other Brain Cancer Care Co-ordinators across NSW.

Support Programs include:

- Curating and hosting our Neuro- oncology Nurses Network Meeting (NONN), we are sharing our expertise with other healthcare professionals, to improve specialised care and support for brain cancer patients across the State.
- Developing a support model for the specific needs of low-grade glioma sufferers and their families.

The TBCG is unique because:

- The focus on brain cancer combined with the synergy arising from medical oncologists, radiation oncologists, surgeons, researchers, nurses, patients and carers all working together for a common goal – improved outcomes for brain cancer patients.
- Clinical Board Directors representing all the disciplines in the treatment of brain cancer, providing invaluable expertise and insight for effective collaboration and support.
- Complementing the clinical specialists are experienced non-clinical Board Directors with commercial and organisational skills.
- A key feature is the operational focus on directing clinical expertise to shape and deliver impactful programs.
- By partnering with organisations that share the TBCG's vision and values, to raise awareness and to fund our programs, results can be achieved in an efficient manner.
- Being co-located with a research institute (Kolling Institute), enables partnering of researchers with clinicians, the ideal environment for bench-to- bedside research.

The Brain Cancer Group is focused on improving patient outcomes across the spectrum – from patient care to working towards finding a cure for this devastating disease. They do this by taking a multi-disciplinary and collaborative approach to deliver meaningful programs which are aimed at improving the lives of those affected by brain cancer, from care2cure.



TBCG Board of Directors (L-R)
 Dr Jonathon Parkinson Neurosurgeon, TBCG Director;
 Mrs Tracey O'Donoghue Accountant, TBCG Director / Company Secretary;
 A/Prof Michael Back Radiation Oncologist, TBCG Director;
 Dr Raymond Cook OAM Neurosurgeon, TBCG Chairman.

TBCG Board of Directors (L-R)
 Dr Helen Wheeler Medical Oncologist, TBCG Director;
 Mr Richard Ryan CEO North Shore Private Hospital, Ramsay Health, TBCG Director;
 Mrs Suzane Peponis-Brisimis Business person and community representative, TBCG Director.
 Dr Adrian Lee Medical Oncologist, TBCG Director.

The Brain Cancer Group 6th Awareness Raising Event.

NSW Parliament House – 22 August 2023

In Association with Brain Tumour Alliance Australia (BTAA)

The Brain Cancer Group (TBCG), in partnership with Brain Tumour Alliance Australia (BTAA), hosted its 6th Annual Awareness Raising Event on Tuesday, August 22, at the NSW Parliament House. This event was kindly hosted by the Hon. Sophie Cotsis MP, the NSW Minister for Industrial Relations, Work Health and Safety. This awareness raising event aims to educate, advocate, and foster unity among patients, caregivers, medical specialists, and community leaders. We come together to acknowledge the profound impact of brain cancer has on individuals and their families and that more needs to be done.

Open to the public, the event commenced with a warm gathering at the Fountain Court, where attendees enjoyed light refreshments before moving into the Theatre for the official proceedings.

Dr. Adrian Lee, Director of The Brain Cancer Group and convenor of the event, extended his gratitude to Hon. Sophie Cotsis MP for her unwavering support, dating back to 2016 when she graciously invited the group to hold their awareness raising event at Parliament. He expressed his appreciation to all present and acknowledging esteemed guests including the Hon. Ryan Park, NSW Minister for Health and Minister for Regional Health; Zoë Baker, Mayor of North Sydney; Carolyn Corrigan, Mayor of Mosman, and representatives from BTAA, such as Catherine Hindson, former Chairperson and current Vice-Chair.

As parliamentary host, Ms. Cotsis extended a warm welcome to all attendees and commended Suzane Peponis-Brisimis, Director of TBCG and Founder of the White Pearl Foundation. The White Pearl Foundation is instrumental in raising funds for The Brain Cancer Group's vital research program. Ms. Cotsis applauded Suzane's tireless work and her "strong advocacy." Ms Cotsis emphasized the tremendous challenges faced by healthcare professionals in their pursuit of giving patients a second chance at life, much like the opportunity she herself received five years ago when diagnosed with breast cancer.

Subsequently, the Hon. Ryan Park, NSW Minister for Health, delved into the government's pivotal role in cancer care and research. He expressed that brain cancer is a policy priority for NSW and also highlighted the urgency of advancing research on rare, often lethal cancers that profoundly affect individuals. Mr. Park's presence underscored the government's steadfast commitment to supporting cancer research.

The event's keynote speakers, Jess Hill and her husband David Hollier, delivered a deeply moving account of their personal journey as a patient and caregiver. The candid sharing was incredibly engaging and had everyone completely captivated. Ms. Hill, an award-winning journalist, author, and ten-year survivor of brain cancer, recalled her diagnosis in 2012 while serving as a Middle East correspondent for The Global Mail. She vividly described the physical and emotional toll of her journey, from her first seizure aboard a flight, to her successful surgery, and the resurgence of her tumour in 2020, just three years after the birth of her daughter. Today, Ms. Hill faces her last round of chemotherapy with courage and resilience.

Mr. Hollier, a Psychotherapist and counsellor, offered his unique perspective on their shared journey, emphasizing the importance of personal narratives and beliefs in navigating such challenges. He explained, "There are facts and then there's the way we interpret them and what we need to believe is possible." His insights resonated with the audience, and he concluded with a heartfelt message to lean on the support of friends and family.

Guest speaker Associate Professor Haryana Dhillon, from the University of Sydney and Scientific Advisory Committee Chair of Psycho-oncology Co-operative Research Group (PoCoG), delivered an informative lecture on the BRAINS (Brain Cancer Rehabilitation, Assessment, Interventions for Survivorship Needs) portal. This valuable resource aims to offer support and foster positive change for individuals affected by brain cancer. Professor Dhillon shared insights into how the portal identifies service gaps, provides information to patients, professionals, and caregivers, and addresses the cognitive, emotional, and physical effects of brain cancer.

Concluding the event, Associate Professor Michael Back, a radiation oncologist and Director of TBCG, extended heartfelt thanks to all attendees for their support and participation in this impactful awareness-raising event.

The successful event culminated with attendees enjoying refreshments in the Theatre foyer, fostering connections, and continuing the vital conversation around brain cancer awareness and research.

The event's presentations are available at the Brain Cancer Group's website as well as their YouTube Channel.
<https://youtu.be/6-wNJuGuSZw>

Shanes B Dressup Fundraiser

Recently Shane who works at Ripcurl on the Surf Coast held a workplace fundraiser for the BTAA. Shane writes:

"Hi , my name is Shane and I just wanted to write to you guys to say a big thank you for what you do and the recognition you give to brain tumour sufferers and their immediate families.

I have just witnessed first hand the effects of a brain tumour having watched my wife be diagnosed late in November 22, followed by surgery three weeks later.

The fear on her face when she was sitting in the chair about to go in for a craniotomy remains with me.

Leading up to her diagnosis the hardest thing was, at that time, we were not quite sure of the outcome. I remember sitting my kids down and my youngest boy said "Does this mean mum's going to die". How was I to answer this ?

We were lucky, her brain tumour (Meningioma) was benign. Her recovery has been slow and hard to watch, especially her headaches as it is dreadful to watch her suffer from them. Sitting alongside my wife the day after her surgery, holding her hand, little did she know I was there and that I had shed tears of relief knowing my kids still had their mum, and I still had my wife.

I decided then that I wanted to give something back. When looking through social media, I stumbled across BTAA and liked how they also included the families of sick ones.

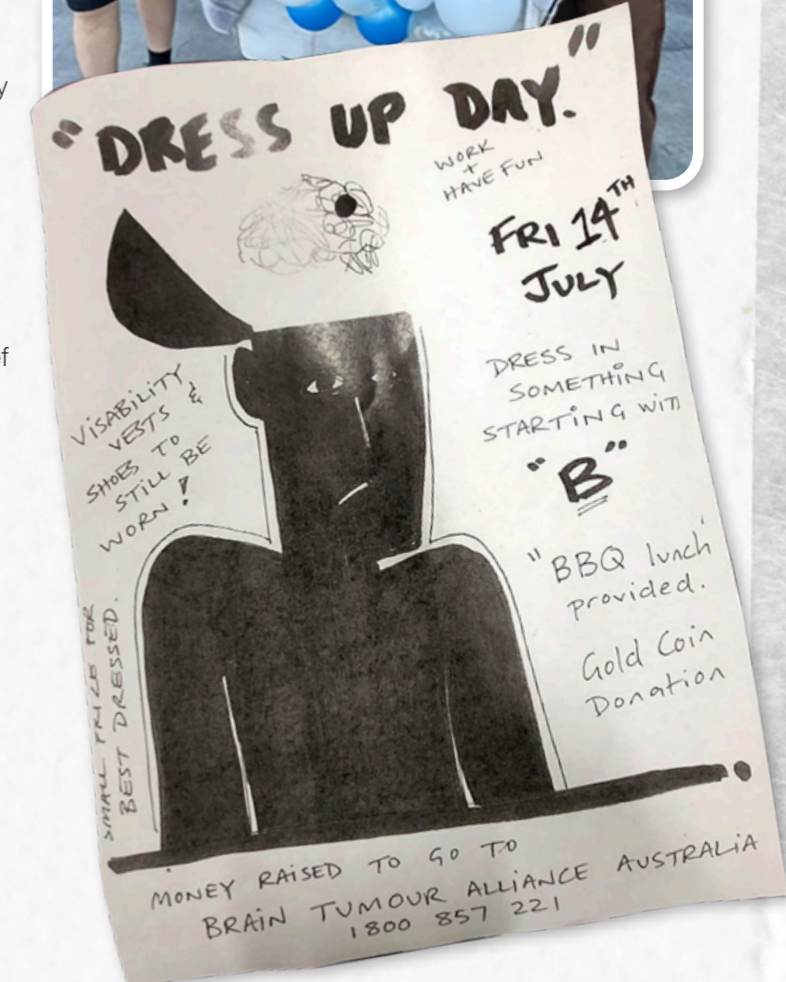
I spoke to my boss about having a dress up to raise a few dollars. Something starting with B was the theme, how obvious. It just gained momentum at a rate of knots and people I knew in the community who had businesses, who knew my wife's plight ,jumped on board with donations, so it became a silent auction on top of dress up.

The day was a great success, I was anticipating to collect at least \$150 or \$200, **but we raised \$4,469.45** which has been forwarded to your bank account you gave me.

I really hope it helps and it also helps others.

Once again I'm proud of my effort and the efforts and donations of everyone involved that day.

Thanks Shane".



THANK YOU FOR YOUR AMAZING EFFORT AND CONTRIBUTION, SHANE & RIP CURL. SURF COAST TEAM! — BTAA



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

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
www.btaa.org.au



Brain Tumour Alliance Australia



@BrainTumourAA



Search 'BTAA' on YouTube



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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