HEAD TO THE HILL 2024 EDITION

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

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HEAD TO THE HILL 2024

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CHAIR'S REPORT

Head to the Hill 2024

The Head to the Hill event is the Australian brain tumour community's opportunity to collectively advocate to government. The event is about ensuring that we have a united voice on the challenges experienced by our community and to show solidarity in our commitment to see them changed.

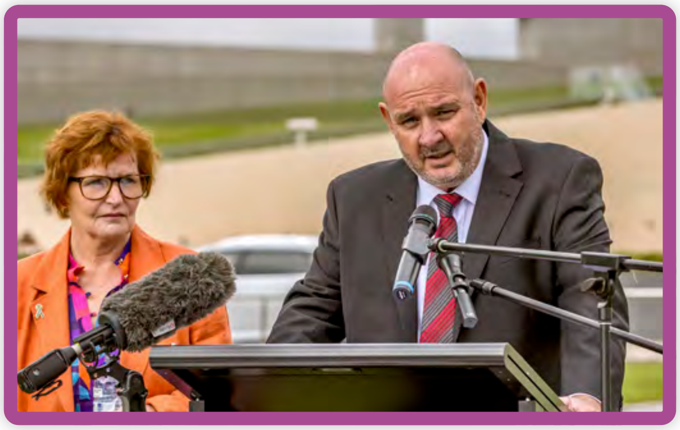
Change for our community – and all other communities like ours – only happens through advocacy. Advocacy can happen through united not-for-profit organisations or through one-on-one discussions with health professions, work colleagues, friends and families or your local member. The important thing is that we all take the opportunity to advocate – via whatever means – whenever we can.

Good advocacy does not always bring change – at least, it can take a long time. There are reasons for this. It may be that the issues are complex, expensive and difficult to resolve. It can also mean that the stakeholders that can bring the change – mainly governments – either don't understand the problem or believe other problems are a higher priority.

An example of this is the announcement of the Australian Cancer Nursing and Navigation Program (ACNNP). The ACNNP seeks to deliver a national program that will provide cancer patients and families with a range of nurse and navigator services through their respective survivorship journeys. It is an ambitious and important program. There will be benefits for our community. However, it is highly unlikely to meet the needs of our most vulnerable.

BTAA began formally submitting requests to government for dedicated brain cancer nurses and coordinators since 2011. These submissions and the call for brain tumour navigators have continued for many years. Despite this, the Australian brain cancer community was not engaged or aware of the program and has no formal representation on the ACNNP as it continues to design and implement its solution.

At the 2023 Head to the Hill event, I included in my speech that one of our highest priorities – in parallel with research – is to implement a dedicated national brain tumour nurse navigator/coordinator framework in Australia. The following speech from the federal government, announced the ACNNP – we were completely unaware of the program. This was unfortunate – at best.



There is a number of brain cancer nurse coordinators in allied health systems in Australia. Some NFP – such as, the Mark Hughes Foundation, Brain Cancer Group, COGNO and others – fund dedicated brain tumour nurses and coordinators in hospitals. These fill a gap but we need a national approach.

The fact that the brain cancer community was caught unaware of the ACCNP and were not engaged prior or during is an issue that we need to resolve. We will continue to now seek to readdress the situation and attempt to ensure our needs are met through the program or via other means.

Notwithstanding, it does mean we need to look at reasons for this happening and understand why our community fell through the cracks. We can then identify the cause and implement advocacy strategies to try and ensure it does not happen again.

Our challenges – irrespective of the means – need to always be heard. Our advocacy will change the brain tumour survivorship journey for our patients, families now – and, in the future.

Craig

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.

Vale Sarah Mamalai

Susan Pitt - Founding member of BTAA

Brain tumour advocate Sarah Mamalai has died in August 2024.

BTAA extends our thanks to the Mamalai boys Joseph and William for their work for our brain tumour community. Sarah and Oscar, their families, their friends, and their families and friends have worked tirelessly since her diagnosis.

Sarah was a long-term survivor of grade 4 brain cancer, diagnosed in 2007. She was a young mum with two boys aged four and 18 months. She was told she had about three to 18 months to live. She did not accept that. Sarah had a second craniotomy in Sydney just six weeks after her first in Canberra after seeing Dr Charlie Teo.

Sarah spent the next 17 years doing all she could to raise her boys, and to raise awareness of the challenges faced by those living with brain cancer. She was an excellent communicator, intelligent and driven by a powerful responsibility to tell her story and to effect change.

In the early years after diagnosis she attended BTAA support group and many events in Canberra where she met others living with the disease.

In May 2008, a year after diagnosis, Sarah trekked Kokoda, with a lot of help from her friends. Together with 13 friends and family she raised $80,000 for the Cure Brain Cancer Foundation.

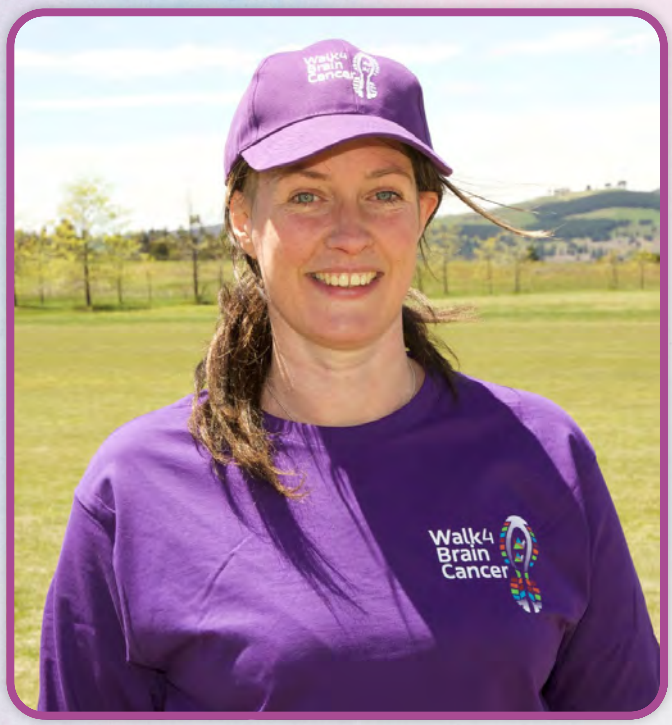
In 2010 Senator Bilyk hosted the launch of the BTAA/beyond blue fact sheet on Brain Tumours, Depression and Anxiety. BTAA appreciated Sarah's courage in telling her story.

Sarah told the launch audience that depression was like the 'dirty secret' of brain tumour diagnosis and treatment. She said "We weren't warned to be vigilant to the signs of depression which can be triggered by the diagnosis itself or by the intensive treatments themselves – no wonder my poor brain snapped. "Sarah spoke out to tell patients that even on the darkest of dark days there is always a tiniest of tiny glimmer of hope – and to grasp it. Read more here.

In 2012 Sarah was on the run with her Mamalai Mummas. They ran the Canberra Times Fun Run and also ran the Colour Run in Sydney.

On Friday 22 November 2013 Sarah organised Brainstorming Parliament House – with a visual display of 1600 brainstorm brains. BTAA attended and helped plant the display.

Sarah established Brainstorm for a Cure in 2014, the year she lost five close friends to brain cancer including 15-year-old Dainere Anthoney – her soul sister.



Sarah, with the support of her friend Amanda Fintan, held six party events – Brainstorm for a Cure – A Party for Hope. www.brainstormforacure.com.au

In November 2016 the Australian Senate established the Parliamentary Select Committee into Funding for Research into Cancers with Low Survival Rates. Many organisations and individuals put in submissions. BTAA's submission was number 127. Sarah put in submission number 268.

Sarah wrote "Research could mean 'in the clear' means the suffering is actually over.

It should NEVER be left to struggling patients and their families to try and raise the money to make that happen."

Sarah was full of life and laughs and was very beautiful – with or without hair. She rocked a great henna scalp tattoo and provided useful tips on hair loss on her web site. Sarah had a wicked sense of humour and a wonderful laugh. She and Oscar met at uni where it was love at first sight.

In May 2020 Sarah's husband Oscar died after a sudden illness. Their sons were in year 9 and year 12. Sarah and Oscar's friends and family again rallied around them.

Our community owes Sarah and her family a debt of gratitude. Vale Sarah Mamalai.

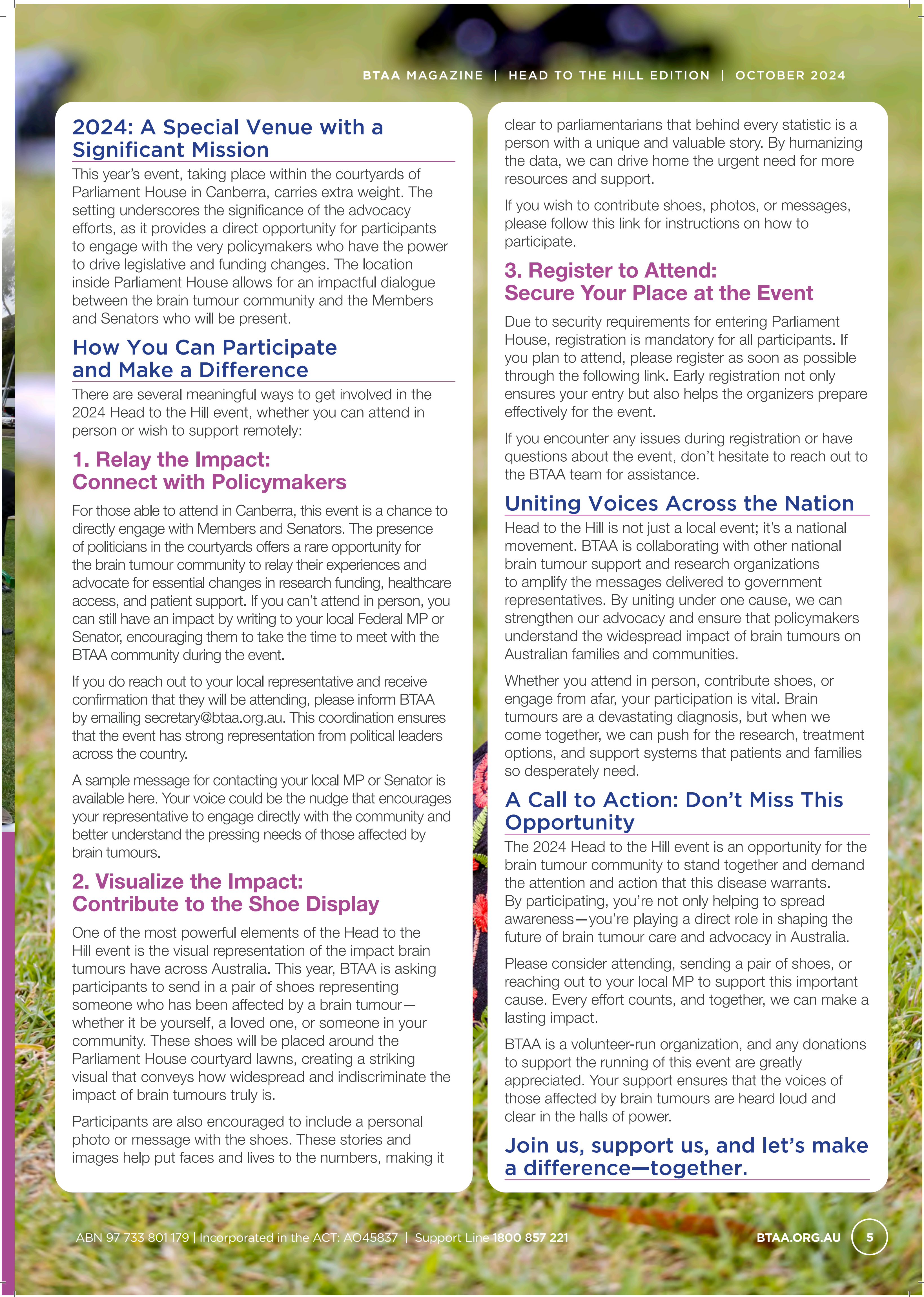
https://www.sarahmamalai.com

Head to the Hill 2024: A Call to Action for Australia's Brain Tumour Community

The Brain Tumour Alliance Australia (BTAA) is once again hosting its pivotal Head to the Hill event, an annual gathering that provides a powerful platform for the brain tumour community. The 2024 event will be held inside the beautiful open courtyards of Australia's Parliament House on Wednesday, 20 November, from 8:00 AM to 12:00 PM. This gathering will not only offer a space for connection and support but also serve as a critical opportunity to amplify the voices of those affected by brain tumours, advocating for increased attention and action from policymakers.

Why Head to the Hill Matters

The impact of brain tumours is far-reaching, affecting people of all ages, genders, and backgrounds. Despite this, brain tumour research remains significantly underfunded compared to other cancers, and those affected often face limited treatment options and inadequate support. Head to the Hill seeks to address these challenges by bringing together survivors, caregivers, healthcare professionals, and supporters in a united call for change. The event is a unique blend of advocacy, awareness, and community support, aiming to highlight the urgent need for increased funding, better access to care, and more comprehensive patient resources.



2024: A Special Venue with a Significant Mission

This year's event, taking place within the courtyards of Parliament House in Canberra, carries extra weight. The setting underscores the significance of the advocacy efforts, as it provides a direct opportunity for participants to engage with the very policymakers who have the power to drive legislative and funding changes. The location inside Parliament House allows for an impactful dialogue between the brain tumour community and the Members and Senators who will be present.

How You Can Participate and Make a Difference

There are several meaningful ways to get involved in the 2024 Head to the Hill event, whether you can attend in person or wish to support remotely:

1. Relay the Impact: Connect with Policymakers

For those able to attend in Canberra, this event is a chance to directly engage with Members and Senators. The presence of politicians in the courtyards offers a rare opportunity for the brain tumour community to relay their experiences and advocate for essential changes in research funding, healthcare access, and patient support. If you can't attend in person, you can still have an impact by writing to your local Federal MP or Senator, encouraging them to take the time to meet with the BTAA community during the event.

If you do reach out to your local representative and receive confirmation that they will be attending, please inform BTAA by emailing secretary@btaa.org.au. This coordination ensures that the event has strong representation from political leaders across the country.

A sample message for contacting your local MP or Senator is available here. Your voice could be the nudge that encourages your representative to engage directly with the community and better understand the pressing needs of those affected by brain tumours.

2. Visualize the Impact: Contribute to the Shoe Display

One of the most powerful elements of the Head to the Hill event is the visual representation of the impact brain tumours have across Australia. This year, BTAA is asking participants to send in a pair of shoes representing someone who has been affected by a brain tumour—whether it be yourself, a loved one, or someone in your community. These shoes will be placed around the Parliament House courtyard lawns, creating a striking visual that conveys how widespread and indiscriminate the impact of brain tumours truly is.

Participants are also encouraged to include a personal photo or message with the shoes. These stories and images help put faces and lives to the numbers, making it clear to parliamentarians that behind every statistic is a person with a unique and valuable story. By humanizing the data, we can drive home the urgent need for more resources and support.

If you wish to contribute shoes, photos, or messages, please follow this link for instructions on how to participate.

3. Register to Attend: Secure Your Place at the Event

Due to security requirements for entering Parliament House, registration is mandatory for all participants. If you plan to attend, please register as soon as possible through the following link. Early registration not only ensures your entry but also helps the organizers prepare effectively for the event.

If you encounter any issues during registration or have questions about the event, don't hesitate to reach out to the BTAA team for assistance.

Uniting Voices Across the Nation

Head to the Hill is not just a local event; it's a national movement. BTAA is collaborating with other national brain tumour support and research organizations to amplify the messages delivered to government representatives. By uniting under one cause, we can strengthen our advocacy and ensure that policymakers understand the widespread impact of brain tumours on Australian families and communities.

Whether you attend in person, contribute shoes, or engage from afar, your participation is vital. Brain tumours are a devastating diagnosis, but when we come together, we can push for the research, treatment options, and support systems that patients and families so desperately need.

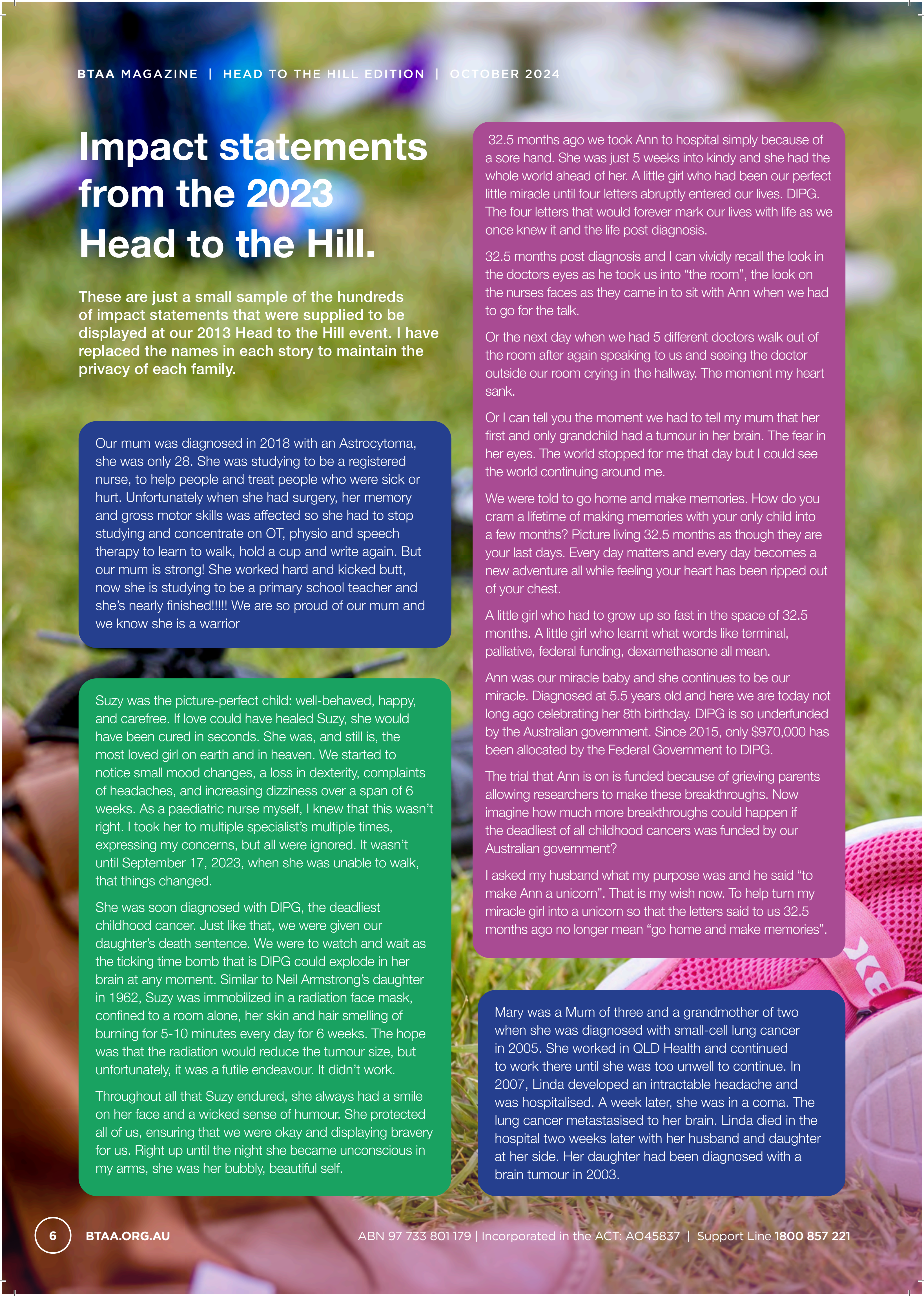
A Call to Action: Don't Miss This Opportunity

The 2024 Head to the Hill event is an opportunity for the brain tumour community to stand together and demand the attention and action that this disease warrants. By participating, you're not only helping to spread awareness—you're playing a direct role in shaping the future of brain tumour care and advocacy in Australia.

Please consider attending, sending a pair of shoes, or reaching out to your local MP to support this important cause. Every effort counts, and together, we can make a lasting impact.

BTAA is a volunteer-run organization, and any donations to support the running of this event are greatly appreciated. Your support ensures that the voices of those affected by brain tumours are heard loud and clear in the halls of power.

Join us, support us, and let's make a difference—together.



Impact statements from the 2023 Head to the Hill.

These are just a small sample of the hundreds of impact statements that were supplied to be displayed at our 2013 Head to the Hill event. I have replaced the names in each story to maintain the privacy of each family.

Our mum was diagnosed in 2018 with an Astrocytoma, she was only 28. She was studying to be a registered nurse, to help people and treat people who were sick or hurt. Unfortunately when she had surgery, her memory and gross motor skills was affected so she had to stop studying and concentrate on OT, physio and speech therapy to learn to walk, hold a cup and write again. But our mum is strong! She worked hard and kicked butt, now she is studying to be a primary school teacher and she's nearly finished!!!!! We are so proud of our mum and we know she is a warrior

Suzy was the picture-perfect child: well-behaved, happy, and carefree. If love could have healed Suzy, she would have been cured in seconds. She was, and still is, the most loved girl on earth and in heaven. We started to notice small mood changes, a loss in dexterity, complaints of headaches, and increasing dizziness over a span of 6 weeks. As a paediatric nurse myself, I knew that this wasn't right. I took her to multiple specialist's multiple times, expressing my concerns, but all were ignored. It wasn't until September 17, 2023, when she was unable to walk, that things changed.

She was soon diagnosed with DIPG, the deadliest childhood cancer. Just like that, we were given our daughter's death sentence. We were to watch and wait as the ticking time bomb that is DIPG could explode in her brain at any moment. Similar to Neil Armstrong's daughter in 1962, Suzy was immobilized in a radiation face mask, confined to a room alone, her skin and hair smelling of burning for 5-10 minutes every day for 6 weeks. The hope was that the radiation would reduce the tumour size, but unfortunately, it was a futile endeavour. It didn't work.

Throughout all that Suzy endured, she always had a smile on her face and a wicked sense of humour. She protected all of us, ensuring that we were okay and displaying bravery for us. Right up until the night she became unconscious in my arms, she was her bubbly, beautiful self.

32.5 months ago we took Ann to hospital simply because of a sore hand. She was just 5 weeks into kindy and she had the whole world ahead of her. A little girl who had been our perfect little miracle until four letters abruptly entered our lives. DIPG. The four letters that would forever mark our lives with life as we once knew it and the life post diagnosis.

32.5 months post diagnosis and I can vividly recall the look in the doctors eyes as he took us into "the room", the look on the nurses faces as they came in to sit with Ann when we had to go for the talk.

Or the next day when we had 5 different doctors walk out of the room after again speaking to us and seeing the doctor outside our room crying in the hallway. The moment my heart sank.

Or I can tell you the moment we had to tell my mum that her first and only grandchild had a tumour in her brain. The fear in her eyes. The world stopped for me that day but I could see the world continuing around me.

We were told to go home and make memories. How do you cram a lifetime of making memories with your only child into a few months? Picture living 32.5 months as though they are your last days. Every day matters and every day becomes a new adventure all while feeling your heart has been ripped out of your chest.

A little girl who had to grow up so fast in the space of 32.5 months. A little girl who learnt what words like terminal, palliative, federal funding, dexamethasone all mean.

Ann was our miracle baby and she continues to be our miracle. Diagnosed at 5.5 years old and here we are today not long ago celebrating her 8th birthday. DIPG is so underfunded by the Australian government. Since 2015, only $970,000 has been allocated by the Federal Government to DIPG.

The trial that Ann is on is funded because of grieving parents allowing researchers to make these breakthroughs. Now imagine how much more breakthroughs could happen if the deadliest of all childhood cancers was funded by our Australian government?

I asked my husband what my purpose was and he said "to make Ann a unicorn". That is my wish now. To help turn my miracle girl into a unicorn so that the letters said to us 32.5 months ago no longer mean "go home and make memories".

Mary was a Mum of three and a grandmother of two when she was diagnosed with small-cell lung cancer in 2005. She worked in QLD Health and continued to work there until she was too unwell to continue. In 2007, Linda developed an intractable headache and was hospitalised. A week later, she was in a coma. The lung cancer metastasised to her brain. Linda died in the hospital two weeks later with her husband and daughter at her side. Her daughter had been diagnosed with a brain tumour in 2003.

John was diagnosed with brain cancer, 2 weeks after he found out him and his partner were expecting their first baby.

He has been fighting brain cancer for over a year now & is taking it head on with so much determination.

We are so proud of him

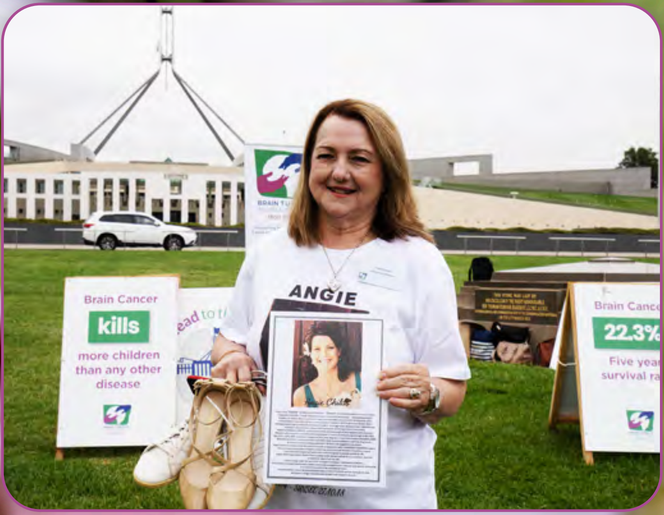
My husband Sean, was diagnosed with Glioblastoma which is the most aggressive, treatment resistant, fast growing terminal brain cancer in August 2022. He has since had brain surgery, 2 rounds of radiation, and 2 lots of chemotherapy. This has immensely impacted on our families lives. We have both had to give up work, live on a pension, raise sixteen year old twins who are still at school. It has emotionally been such a hard journey, financially it has made our life do difficult, and it has been really stressful on every level.

Brian's brain tumour ate him alive from the inside out. It consumed everything from him ... his taste, sight, hearing, thinking and feeling. The vibrant man that I met 35 years' ago was stripped down to a shell. I watched him disappear before my very eyes, and as he clung to me one last time out of sheer desperation, the anger within built up knowing that brain cancer isn't "sexy" enough to attract the funds, media campaigns, celebrity support or sporting fundraisers. There's such an unfairness feeling about brain cancer. You can't fight something that isn't tangible, and brain cancer was going to win from the outset ... it is a life sentence.

My amazing husband Andrew passed away on Tuesday 30 May 2023 from Stage 4 Glioblastoma Brain Cancer at the age of 49. He died 6 months following his tumour removal, radiation, and chemotherapy. We were hopeful his life would be extended to the 14/16 month mark and beyond, however this aggressive cancer is so cruel and fast growing he deteriorated quickly.

Following a major brain bleed and stroke in June 2022 we lived life not knowing he had a tumour growing in his brain. If only we knew then what was to come, we could have planned our lives differently and have some sort of quality time together.

Wendy was diagnosed with ganglioglioma in 2018 at the age of 5. She has completed two chemotherapy protocols: 728 days of chemotherapy. She has had two brain surgeries, 25 MRIs and is currently accessing Trametinib. Wendy has received countless transfusions of blood products. In the five years since diagnosis, Emily has never had a significant period of stability. She has not attended school full-time since prep in 2019. Wendy has a feeding tube to support her hydration and feeding. But she loves her life she plays cricket and soccer, and she makes the best of every day.



The shoes that best represent Brian are not shoes at all, but bare feet. When we travelled around Australia he and kids were barefoot almost the whole time, even on bushwalks in the Kimberley. He was a surfer, a guitarist, a painter, a joker, a thinker, a gardener. He was a loving, caring, hands on dad to our three children. I am so sad he is not here with me to watch them grow up. For a job, Brian was a barrister. Hence these shoes. I think there are lots of people out there who were glad they had Brian on their side when they had their day in court, because he always gave it his best shot. When he was diagnosed with glioblastoma he did everything he could to be here longer for his family. Two brain surgeries, chemo, radiation. The drugs he had to take were horrible, they made him swell up and become much more anxious. He died at home less than two years after he was diagnosed.

Daniela Dwyer Foundation Funds Cancer Test Research

Earlier this year, the Daniela Dwyer Foundation (DDF) launched the Daniela Dwyer Foundation Fellowship, offering a $50,000 grant to support Australian researchers in brain cancer diagnosis and treatment. In March 2024, the inaugural fellowship was awarded to Professor Sudha Rao at the QIMR Berghofer Medical Research Institute, in recognition of her groundbreaking work on a liquid biopsy digital pathology platform (BTAA e-news, April 2024).

Professor Rao expressed the profound impact the grant has made to her research:

"I am honoured to receive the Daniela Dwyer Foundation Fellowship. This support has allowed the Rao Laboratory to accelerate progress of our non-invasive liquid biopsy tests of blood samples to monitor in real-time, cancer progression and provide novel combinations of drugs for patients via personalised medicine approaches. We are very close to getting accreditation for clinical testing so the testing can be utilised by labs around Australia and worldwide.

We are very grateful for the support of the Daniela Dwyer Foundation."

– Sudha Rao, 6 July 2024

The Test

The blood test pioneered by Professor Rao, merges expertise in epigenetics, digital pathology, and cancer cell analysis. This non-invasive liquid biopsy method measures cancer burden and tracks patient responses in real time, and makes ex-vivo drug performance possible.

Designed to monitor "seeder" cells responsible for initiating metastatic brain cancer, and potentially significant in primary brain cancers like glioblastomas, this test represents a significant breakthrough.

Previously impossible to monitor, Professor Rao's team has identified the molecular and protein composition of these cells.

The test's ability to detect these cells and monitor their treatment responses will pave the way for more targeted drug therapies and earlier treatment interventions. It has already shown promise in guiding immunotherapy for melanoma in a preliminary study with a small patient group.

The Foundation

The DDF was established in 2023 in memory of Daniela, who tragically passed away from glioblastoma just 11 months after her diagnosis, at the age of 34. The Foundation's mission is to raise critical funds for brain cancer research, with a focus on enabling earlier diagnosis and treatment options.

Glioblastoma, or GBM, is the most common and deadliest form of brain cancer in adults. It is highly aggressive, with an average survival rate of just 15 months. Currently, only 5% of GBM patients survive five years post-diagnosis.

Given that brain cancer claims more lives among Australians under 40 than any other cancer, the Foundation is dedicated to channelling all funds raised towards this cause. Daniela's legacy is to make a difference in the lives of other people affected by brain cancer.

DDF Fundraising

In June 2024, the Foundation hosted its first Daniela Dwyer Foundation Race Day at Canberra's Thoroughbred Park, raising $32,000. The following month, the second DDF Quiz Night in Perth raised an additional $25,000. In August, Daniela's sister proudly represented the DDF in Sydney's City2Surf run. The success of these and other events has allowed this nascent charity to make a significant impact, raising over $200,000 in its first 18 months.

Thanks to the extraordinary generosity of supporters, the Foundation has provided Professor Rao with an additional $50,000 to upgrade the liquid biopsy digital pathology platform and establish a dedicated testing facility within QIMR. The facility is on the verge of receiving National Association of Testing Authorities (NATA) accreditation, which will enable it to analyse larger patient cohorts. This milestone will greatly accelerate the availability of this test for all cancer patients.

The Foundation takes pride in supporting Professor Rao's research, having contributed $100,000 in crucial funding. This support has been instrumental in transitioning the liquid biopsy digital platform from lab research to clinical application. Both Professor Rao and the DDF are committed to making this test a standard component of routine cancer treatment, ultimately extending patient survival.

For more information on the Foundation and Professor Rao's research, or to make a donation and support the DDF's work, visit danieladwyerfoundation.org.au.

Running the Larapinta Trail in central Australia

An adventure in support of BTAA - By Kate Bown

Before I was diagnosed with a brain tumour, I was a runner. I would wake early and meet friends to run along a trail in the bush near where I lived in Hobart, Tasmania. I wasn't fast, but I was determined. Sometimes I would run until the sound of the city disappeared and my feet grew hot and my heart ached. Running made me feel alive — like I had a tiny blue fire burning in my chest.

When I was recovering from surgery and treatment for a brain tumour (13 years ago now) I longed for the freedom and movement of running. With time I began jogging again, first one minute intervals, then five, until I could run the entire length of the footpath shaped like a crescent moon, just around the corner from my house.

A few years later, my first child was born and over the next six years, three more children arrived. The demands of young motherhood and trail running were hard to combine. But after each birth, I gradually returned to my slow jog around the neighbourhood, and when I was feeling strong again, along the trails in the bush.

Two weeks ago I flew to Alice Springs, in central Australia, with a girlfriend to participate in a four day, 84 kilometre trail running race — Run Larapinta. It was an event we joined to challenge ourselves and to raise funds for BTAA and the brain tumour community in Australia.

The race follows sections of a 210 kilometre walking track called the Larapinta Trail. It weaves through the spectacular West MacDonnell Ranges — a mountain chain that extends as far as the horizon west of Alice Springs, like a backbone, or a restless caterpillar moving across the fiery red desert, the indigenous Dreaming story for this landscape.

The Larapinta Trail is in Arrernte country — the land, sky and waters of the Arrernte, the Aboriginal people who have lived here for 30,000 years and continue to be its custodians.

The landscape was a world away from our cool temperate island home of Tasmania. A bright wide sky — blue, almost green. Tangerine hills caked with rocks. Thick sand the colour of fire. Short grey-green trees, spindle like, some blackened by fire. Thin and spikey grass — viscous and bloody. Gorges that weaved like serpents, full of lush Mallee Eucalyptus trees, native palms and flowers, and pools of deep dark water that reflected the landscape.

Nothing was familar. Even the air was strange. The mornings were cold, a desert surprise, but the sun soon broke over the valleys and brought a brittle and savage heat (33 degrees Celsius). It wicked the water from my body with a hunger.

I hadn't anticipated how hard it would be running in a desert for four consecutive days. Every morning we rose in the dark to eat breakfast, pull on our running gear, stuff trinkets, water bladders and various forms of sugar (jelly beans, gels, energy bars) into our running vests, and catch a bus to the start of the trail.

Each day grew more challenging. The ascents and descents were gruelling. The heat was brutal. Sweat evaporated from my skin so that I was covered in a thin veneer of salt crystals. My feet blistered and each day I stuck more brown strapping tape over them.

It was a real adventure — rapture, exhaustion, endurance. But equally, friendship and salvation.

The final 28 kilometre stage finished at Ellery Creek Bighole — a spectacular outback waterhole surround by high red cliffs and sandy banks. After crossing the blue inflatable arc of the finish line, we walked our shaky legs into the cold dark water. It was glorious. And when our feet were numb, we pushed ourselves under. It was a wonderful way to celebrate the end of a desert running adventure.

We were thrilled to raise over $3000 for BTAA. Thank you to everyone who supported our fundraiser. And to my husband and my mother who looked after our home and our children while I was running.

If you are interested in learning more and supporting our fundraiser, please follow the link below.

Run Larapinta. Help support those affected by a brain tumour

https://www.gofundme.com/f/run-larapinta-help-support-those-affected-by-a-brain-tumour

COGNO, the Cooperative Trials Group for Neuro-Oncology: Transforming Brain Tumour Trials, Research and Care in Australia and Beyond

Established in 2007, the Cooperative Trials Group for Neuro-Oncology (COGNO) is the national organization dedicated to improving outcomes for patients with brain cancer through collaborative multi-site clinical trials, research and advocacy. As an integral part of the Australian brain cancer research landscape, COGNO's work is helping transform the way brain tumours are treated and managed, offering new hope to patients and their families. COGNO has over 1000 members mostly from Australia and New Zealand, including healthcare professionals, researchers, clinical trials experts, consumer and advocates. COGNO collaborates with a wide range of stakeholders such as academic institutions, hospitals and industry partners.

COGNO's mission is "the achievement of better health outcomes for patients and others affected by brain tumours through clinical trials research".

The Importance of COGNO

Brain cancer, though relatively rare, has a disproportionately high impact due to its' aggressive nature and limited treatment options. Glioblastoma, the most common and deadly form of primary brain cancer in adults, has a five-year survival rate of only 5%. The complexity of brain tumours and their resistance to standard therapies, makes research into novel treatment approaches critically important. COGNO plays a central role in this by helping to facilitated and coordinate high-quality clinical trials across Australia, ensuring that the latest research reaches patients efficiently and effectively.

Brain cancer research demands specialized knowledge and collaboration across multiple disciplines, including neurosurgery, medical and radiation oncology, radiology, translational science and supportive care. By bringing together experts from these fields, COGNO fosters a multidisciplinary approach that encourages and supports the development of innovative therapies to improve patient outcomes. COGNO has a trained Consumer Advisory Panel who play a key role in reviewing new concepts and trials brought to COGNO and provides vital consumer perspective on trial committees and research grants.

COGNO
COOPERATIVE TRIALS GROUP
FOR NEURO-ONCOLOGY

How COGNO Operates

COGNO's primary focus is to develop clinical trials that evaluate new treatment strategies, including novel drug therapies, neurosurgical techniques and radiotherapy approaches. Through its extensive network of research sites across metropolitan, regional and rural Australia, COGNO enables all patients to have access to cutting-edge treatments. COGNO also provides focused educational opportunities for healthcare professionals, advocates for brain cancer research funding. COGNO and its leadership is also actively involved in promoting public awareness of brain cancer, and professional awareness of national guidelines for brain cancer optimal care.

COGNO Leadership

Associate Professor Eng-Siew Koh, COGNO Chair
MBBS FRANZCR
Radiation Oncologist, Liverpool Hospital, NSW

Professor Rosemary Harrup, COGNO Deputy Chair
FRACP FRCPA
Director, Cancer and Blood Services
Royal Hobart Hospital, Tas

Professor Hui Gan, COGNO Scientific Advisory Chair
FRACP PhD
Medical Oncologist
Austin Health, Vic

Dr Vino Pillay, COGNO Executive Officer
PhD
Melbourne, Vic

Key Achievements and Ongoing Initiatives

- Recruited over 900 participants to COGNO-led trials in brain cancer
- Activated over 141 study sites across our trial portfolio
- Secured over $16m in competitive grant funding for COGNO-led trials, with involvement in other imaging studies, supportive care research and basic science

COGNO has spearheaded several landmark clinical trials both Australian-led and with international collaborators in Europe and North America that have directly influenced the treatment of brain cancer.

The CATNON trial, a phase 3 randomised trial

Australian lead: Prof Anna Nowak, WA

CATNON evaluated the use of chemotherapy and radiotherapy in treating a specific type of brain tumour known as grade 3 anaplastic glioma. The findings from this trial have led to changes in standard treatment protocols worldwide.

Adjuvant and concurrent temozolomide for 1p/19q non-co-deleted anaplastic glioma (CATNON; EORTC study 26053-22054): second interim analysis of a randomised, open-label, phase 3 study - The Lancet Oncology

The MAGMA trial, a phase 3 randomised trial

Australian lead: Assoc Prof Craig Gedye, SA

Australia's largest GBM trial ever with 331 participants across 28 Australian sites!

MAGMA evaluated the use of both early (neoadjuvant) Temozolomide (before radiation) as well as extended Temozolomide beyond the standard 6 months. Recruitment completed in July 2024 with final results awaited.

See protocol publication:

Multi-Arm GlioblastoMa Australasia (MAGMA): protocol for a multiarm randomised clinical trial for people affected by glioblastoma | BMJ Open

The LUMOS2 trial, a phase 2 randomised trial

Low & Anaplastic Grade Glioma Umbrella Study of MOlecular Guided TherapieS (LUMOS-2)

Australian lead: Prof Hui Gan, VIC

COGNO is at the forefront of investigating personalized medicine approaches. LUMOS2 is an exciting Precision Oncology study trial for participants with recurrent lower grade (2 or 3) IDH-mutant glioma currently recruiting across Australia, with up to 14 trial sites nationally. In a first for COGNO, successful funding has been secured to expand the LUMOS2 trial across Canada, which will open in the coming months. Participants undergo repeat surgery, have their tumour profiled and are then assigned to a drug intervention based on the profile of their tumour. There are currently 4 interventional arms in the trial.

The Future of Brain Cancer Research in Australia

Looking ahead, COGNO aims to expand its clinical trial portfolio in both malignant (primary glioma and secondary metastatic cancers) as well as benign brain tumours. COGNO is also committed to improving access to clinical trials for under-represented populations, including those in regional and remote areas, as well as culturally and linguistically diverse populations, to help ensure that all patients benefit from the latest advances in treatment.

COGNO's work is more than just research; it's about providing hope. For patients diagnosed with brain cancer and their families, COGNO represents a lifeline—a network of committed members with significant expertise dedicated to finding better treatments and ultimately, a cure. By continuing to drive collaborative research, COGNO is making a positive impact on the lives of Australians affected by brain and spinal tumours, paving the way for a future to successfully combat this devastating set of diseases.

To find out more about COGNO, including application for free membership, please visit https://cogno.org

You can help further the work of COGNO by donating today!

DONATE TO COGNO (MYCAUSE.COM.AU)

The Brain Cancer Centre team (Pictured)

Mark Hughes Foundation Research Investment

Off the back of this year's 'Beanie for Brain Cancer' campaign, the Mark Hughes Foundation (MHF) has announced a $1m investment to bring two of Australia's leading brain cancer research centres together in their mission to accelerate progress towards a cure.

The MHF Centre for Brain Cancer Research at the University of Newcastle and The Brain Cancer Centre based in Melbourne have formed a partnership to help find solutions sooner.

With brain cancer as the leading cause of cancer death in children, and in adults aged under 40 in Australia, this powerful partnership will pool resources and combine research efforts to pursue better outcomes for brain cancer patients.

Established by Mark and Kirralee Hughes, after the former Newcastle NRL player was diagnosed with a high-grade brain cancer in 2013, the MHF is this year highly focused on collaboration.

Chair and Director of the MHF Centre for Brain Cancer Research at the University of Newcastle, Professor Mike Fay, is passionate about working together to find a solution.

"We know we can't do this alone and in 2024 we are focusing on expanding and deepening our research partnerships to fast track a solution for brain cancer," Professor Fay said.

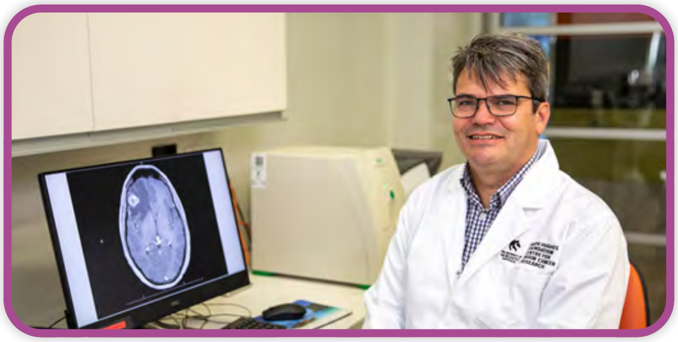
Due to the enormous success of the 2024 campaign, and in particular the support of the NRL through the Beanie Round, the $1m MHF announcement includes the establishment of a National Collaboration Seed Fund to support a series of shared projects aimed at addressing immediate collaborative research needs.

Mark Hughes said bringing together brilliant leaders, experts and innovators was key to solving the brain cancer puzzle."By embracing a 'one team' mentality where competition gives way to collaboration, we will make progress in the fight against brain cancer," Mark said.

The Collaboration Seed Fund's first project will support the MHF Centre to become an official collaborative partner of The Brain Cancer Centre's Brain Tumour Registry Australia INnovation and Translation Registry (BRAIN Registry).

Established with the intent of supporting a broad range of collaborative research projects and to link datasets and research endeavours, the BRAIN Registry is the first large clinical cancer registry dedicated to brain tumour patients in Australia and New Zealand. It captures clinical data on patients diagnosed with brain tumours, from diagnosis and throughout their brain cancer journey.

"Our partnership with The Brain Cancer Centre is an invaluable opportunity made possible by the strong, ongoing support of Mark and Kirralee Hughes of the Mark Hughes Foundation," Professor Fay said.



Chair and Director of the MHF Centre for Brain Cancer Research at the University of Newcastle, Professor Mike Fay.

The Brain Cancer Rehabilitation Assessment Interventions for Survivorship Needs (BRAINS) Program


The BRAINS Program team.

The BRAINS program is a $4.9mil Medical Research Future Fund (MRFF) funded program of work aimed at delivering better survivorship and supportive care to people affected by brain cancer and their caregivers.

BRAINS Studies currently open for recruitment:

Beyond Brain Cancer

We are looking for anyone aged 15-40 who has experienced brain cancer and has finished treatment that was successful in treating, controlling, or removing brain tumour to help us improve an online group-based support program. We also want to hear from carers/ family members and health professional who support this population.

To find out more and sign up, click the link or scan the QR code:
https://www.behaviouralsciencesunit.org/beyond-brain-cancer.html

If you have any questions, please send us an email:
recapturelife@unsw.edu.au

Carers: Personality and Behaviour Change

We are looking for current or past carers and family members of adult patients with brain tumour related personality and behaviour changes. We want to interview carers to better understand their experiences and support needs. These interviews will help us to understand how to manage these changes and will help us to develop supports for patients and their carers.

For more information or to participate,
please contact Emma McDougall
emma.mcdougall@curtin.edu.au,
visit https://bit.ly/carers_personality or scan the QR code.

Below are the latest publications from the BRAINS Program

Access to psychosocial support for people with brain tumor and family members: Healthcare professional perspectives

Authors: Katarzyna Lion, Haryana Dhillon, Eng-Siew Koh, Mark Pinkham, Joanne Shaw, Georgia Halkett, Tamara Ownsworth for the BRAINS Program Investigators

Published: Psycho-Oncology. 2023 April;1-9

What we found: Access to psychosocial support for people with brain tumour varies. It depends on the type of tumour, the stage of illness, and where they are getting help. People with high-grade glioma have more support options. People who have lower-grade gliomas often need to find support on their own. It's easier to get help during the acute phase, but finding ongoing support may be tough.

Important things we learned: Not everyone who needs psychosocial support can get it, particularly those with lower-grade gliomas. Support should be tailored for each person and their family. Healthcare professionals are often not trained to handle the emotional and counselling needs of these patients. More training is needed for them.

Psychosocial interventions for personality and behavior changes in adults with a brain tumor: A scoping review

Authors: Emma McDougall, Lauren Breen, Haryana Dhillon, Georgia Halkett

Published: Neuro-Oncology Practice, 2023 June

What we found: There aren't many programs to help people with brain tumour and their carers deal with personality and behaviour changes.

Important things we learned: The few programs that exist do help patients and carers manage these changes. We need more research to find the best ways to support people with brain tumours and their carers. Treatments for conditions like dementia or brain injury might also help, but we need more research to be sure.

A nurse-led intervention for carers of people with high grade glioma: a case series of carers reporting high distress

Authors: Georgia Halkett, Emma McDougall, Melissa Berg, Jenny Clarke, Haryana Dhillon, Elizabeth Lobb, Jane Phillips, Peter Hudson, Mona Faris, Rachel Campbell, Joanne Shaw, Elisabeth Coyne, Brian Kelly, Tamara Ownsworth, Dianne Legge, Anna Nowak

Published: Journal of Neuro-Oncology Practice,17 April 2024

What we found: Carers' stress and needs change over time. They need regular check-ups and support. Nurses play a key role in spotting carers' needs, giving help and making referrals.

Important things we learned: We should regularly check how carers are to make sure we don't miss their needs. Carers need special support at the time of diagnosis and help beyond just managing cancer symptoms. We need more research to support carers with practical needs and managing changes in behaviour and personality.

"It was never about me": A qualitative inquiry into the experiences of psychological support and perceived support needs of caregivers of people with high-grade glioma

Authors: Katarzyna Lion, Anthony Jamieson, Abigail Billin, Stephanie Jones, Mark Pinkham, Tamara Ownsworth

Published: Palliative Medicine. 2024 June

What we found: Caregivers put their loved ones' support needs above their own. Carers may not look for or accept help for their own needs. Carers have unmet needs for emotional, informational and practical support. They rarely get psychological help for themselves and almost never receive support for grief.

Important things we learned: Caregivers want easy access to care coordination, palliative care services, practical help and support specific to brain tumours. There are opportunities for primary care providers to check on caregivers' well-being and offer support and referrals.

Unmet needs in people with high-grade glioma: defining criteria for stepped care intervention

Authors: Mona Faris, Haryana Dhillon, Rachel Campbell, Georgia Halkett, Annie Miller, Raymond Chan, Helen Haydon, Ursula Sansom-Daly, Eng-Siew Koh, Tamara Ownsworth, Anna Nowak, Brian Kelly, Robyn Leonard, Kerryn Pike, Dianne Legge, Mark Pinkham, Meera Agar, Joanne Shaw

Published: JNCI Cancer Spectrum, 2024 Aug, 8(4)

What we found: The unmet needs of people with high grade glioma can be sorted into four groups: no need, low need, moderate need and high need. These groups will allow health care services to focus on helping those with the greatest needs first.

Important things we learned: By knowing how many people might need support at each level, health services can better plan and focus resources. This can be helpful in busy health care systems or those that are short on resources.

What factors can improve preparedness in carers of people with High Grade Glioma?

Authors: James Clarke, Georgia Halkett, Emma McDougall, Haryana Dhillon, Elizabeth Lobb, Jane Philips, Peter Hudson, Anna Nowak on behalf of the Care-IS team

Published: Journal of Neuro-Oncology Practice 2024 June

What we found: Carers need help in five main areas when preparing to care for someone with high-grade glioma. These areas are: carer needs, giving emotional and practical care, dealing with uncertainty, handling the illness as it gets worse, and managing end of life care.

Important things we learned: It is important to help carers prepare for and cope with changes after a high-grade glioma diagnosis.

Impact of Cognitive Rehabilitation on Cognitive and Functional Outcomes in Adult Cancer Survivors: A Systematic Review

Authors: Zev Nakamura, Nadeen Ali, Adele Crouch, Haryana Dhillon, Angela Federico, Priscilla Gates, Lisa Grech, Shelli Kesler, Leila Ledbetter, Elisa Mantovani, Samantha Mayo, Ding Ng, Lorna Pembroke, Kerryn Pike, Stefano Tamburin, Chia Tan, Yi Toh, Yesol Yang, Diane Ah, Deborah Allen

Published: Seminars in Oncology Nursing, July 2024

What we found: Cognitive rehabilitation programs are helpful for cancer survivors who have cognitive difficulties. There are two main types used: strategy and cognitive training. These types differ in how they are used (in person vs remote delivery). Also, the things they are good at helping to make better.

Important things we learned: Programs used (strategy or cognitive training) should match the things you are trying to make better. It can be hard to access these programs because there aren't a lot of professionals trained in them. There often isn't funding and not all healthcare providers know about the programs. Nurses can help make patients and healthcare providers aware of the programs and how to use them.

Further information about the BRAINS Program can be found on our website:

www.pocog.org.au/the-brains-program

Social Media Can Help

After receiving a brain cancer diagnosis, your entire world changes. We often tend to feel overwhelmed and isolated in this new world of doctors, nurses and other medical professionals. We may start to search for answers to the many questions we now have. While medical professionals provide us with that invaluable care, there is a unique solace and strength found in connecting with others who understand the journey. This is where social media emerges as an unexpected ally, offering a source of community where support, information and hope can be found.

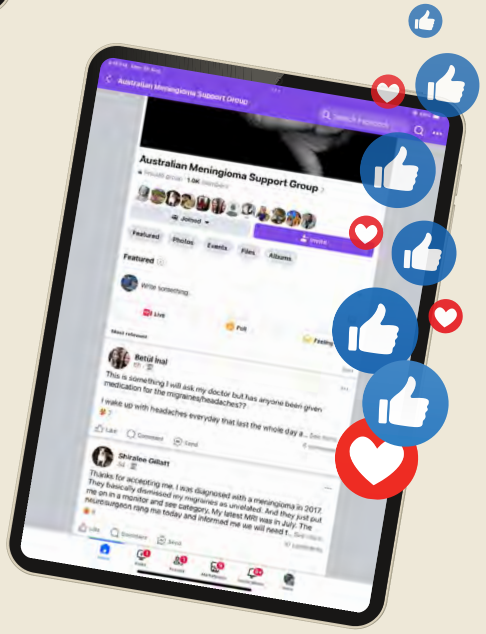
Please welcome Vanessa Schiller who has a Meningioma & being treated at Royal Darwin & Macquarie Hospital

Social media platforms can get a lot of bad press, but they are a great way for brain tumour patients to stay in touch, offer support and keep up to date with the latest events and news. Brain tumours are thankfully rare, so in-person support groups often only operate in major cities, so social media is an ideal way to find your brain tumour community, especially if you live some distance from the city centre or in a rural or remote location.

Platforms like the Brain Tumour Alliance Australia's (BTAA) Facebook and Instagram pages offer a wealth of information, from the latest research breakthroughs to practical advice on managing symptoms and treatments. But perhaps more importantly, they foster a sense of community.

Sharing stories of courage and resilience can be incredibly empowering. Reading about others who have faced similar challenges can provide inspiration and hope. Sometimes just knowing that you are not alone can make a world of difference.

The Brain Tumour Support Group Australia and Meningioma Support Group Australia offer more focused communities. These platforms allow patients to connect with others and engage or contribute to discussions as much as you feel comfortable to do so. What is great about these groups is the ability to connect with others experiencing similar or the same types of tumours. Sharing experiences and information with people who truly understand your situation can provide a level of comfort and support that is hard to find elsewhere.



This is something I will ask my doctor but has anyone been given medication for the migraines/headaches??

I wake up with headaches everyday that last the whole day a...

Thanks for accepting me. I was diagnosed with a meningioma in 2017. They basically dismissed my migraines as unrelated. And they just put me on in a monitor and see category. My latest MRI was in July. The neurosurgeon rang me today and informed me we will need t...

The American Brain Tumour Association Facebook page extends the reach of support beyond our shores. Connecting with patients from different countries can offer a broader perspective on the challenges and triumphs of living with a brain tumour. It is a good reminder that while the journey may be unique, the human experience of facing adversity is universal.

Social media is not just about receiving support; it's also about giving back. By sharing your experiences, you can help others feel less alone and provide valuable insights. Your story can inspire hope, offer encouragement, and even educate others about the realities of living with a brain tumour. In addition to emotional support, social media can provide practical benefits. You might discover new treatment options, learn about clinical trials, or find information about support services in your local area. You can connect with researchers, advocates, and other professionals who can offer valuable guidance.

While social media can be a powerful tool, it's important to use it mindfully. Be aware of the potential for misinformation and focus on credible sources. It's also important to protect your privacy and avoid sharing personal information that could compromise your safety.

Connecting with others who understand your journey is a crucial part of coping with a brain tumour diagnosis. Social media offers a unique opportunity to find your tribe, share experiences, and build a support network that can make a significant difference in your life.

So, take the first step. Join a brain tumour support group on social media. Share your story, ask questions, and engage with others. You might be surprised at the strength, hope, and camaraderie you find.

Remember, you're not alone. There is a community waiting to welcome you with open arms.

NEED SUPPORT NOW?

PHONE 1800 857 221

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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

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