



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

1800 857 221

OCT 2022

BTAA.ORG.AU



“I SIMPLY WANT TO LIVE AS
A NORMAL 19-YEAR-OLD
TEENAGER.”

SIENNA'S

JOURNEY

INSIDE THIS EDITION

**A GUIDE TO
CARING FOR
CANCER CARERS**

**BTAA'S ELDER
STATESMAN TURNS
EIGHTY**

DIPG IN AUSTRALIA

**BRAIN TUMOURS
AND COVID**

THIS MAGAZINE WAS PRODUCED WITH THE ASSISTANCE OF DONATIONS

SAVE THE DATE - 16TH OCTOBER 2022



Patient Education & Information Forum

Sunday 16 October 2022 / 10am - 2:30pm

The Hilton 190 Elizabeth Street, Brisbane

EARLY REGISTRATION

btaapatientforum22.eventbrite.com.au

EVENT PROGRAM

9.30am-10.00am Registrations

10.00am - A/Prof Eng-Siew Koh: Forum Opening

- Dr Frank Saran: Medulloblastoma - A journey through time
- A/Prof Matthew Foote: Radiation Therapy and Stereotactic Radiosurgery for Brain Tumours
- A/prof Craig Gedye: Latest Trials - PICCOG, MAGMA and LUMOS2
- Q&A
- A/Prof Haryana Dhillon: Portals & Pathways. Can we deliver integrated support to people with brain tumours and their families?

12.00pm - 12.45pm Lunch

12.45pm - A/Prof Kerry Pike: Strategies to manage Memory and Thinking Difficulty after Brain surgery

- Dr Helen Hayden: Website for carers
- Dr Elizabeth Coyne: Balancing recovery: Acknowledging the challenges and looking for new ideas
- Fiona Hassman: National Advocacy Service: Accessing NDIS, My Age Care, Centrelink, Carer Gateway

2.15pm-2.30pm | Q&A and Closing Remarks



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**The Brain
Cancer Group**

LETTER FROM THE CHAIR

This year has again been a very active and successful one for the BTAA. Despite activities being restricted by the pandemic, we have been able to make considerable progress on new initiatives, as well as maintain our current services to brain tumour patients, carers and their families across Australia. This includes all of our four areas of endeavour; Support, Inform, Connect and Represent.

Our support services have again been widely utilised. The 1800 number for brain tumour patients and caregivers to provide support and peer to peer advice logged more than 200 calls during the year. Many thanks to Billy Williams, Peter Ramstadius and Janet Mcaliff, who work together to provide this 24/7 service.

More than 100 patient and carer welcome and support packages were posted to people across the country. These free packages contain a selection of the best resources from around the world as well as our own Australian resources developed in conjunction with health professionals across the country.

There has also been a consistent steady increase in subscribers and members throughout the year. Subscribers receive a monthly e-news and a biannual magazine focusing on patient stories, news, research and events both at home and around the world. Members are able to contribute to the operation of the BTAA and can vote in officer elections.

Support groups are conducted in most capital and some regional areas for brain tumour patients. These are either run by the BTAA or supported by us. A full list of Australian support groups is available on the BTAA webpage. Special thanks to Gery Tye from the Sydney support group for organising the Sydney ZOOM meetings when COVID may have caused the cancellation of these essential meetings. The BTAA also provided our ZOOM account for other support groups to run as well.

The BTAA works to inform members of the brain tumour community, from a patient perspective, of the latest research, support programs and helpful day to day information. The BTAA conducted a full day patient forum in conjunction with the COGNO Annual Scientific Meeting in 2021, as well as three highly successful patient education forums in conjunction with The Brain Tumour Group. These focused on Meningiomas, Oligodendrogliomas and Molecular Medicine. These forums are available to watch in full on the BTAA website and The Brain Tumour Group website. A report on the most recent forum is in this magazine.

The BTAA Magazine has a circulation of 1500 readers and the E-news has more than 2000 subscribers. It is a facility for all brain tumour groups to effectively communicate their programs and events for free to the largest brain tumour community in the country.

Our social media stream, Facebook, Twitter and Instagram has been re-energised in the past few years thanks to the hard work of Amanda Griffin, Diane Dunn, Bell Ross and Pam Hubner. These sites are always current with up to the minute news and information and have a large following. Di Pooley is the moderator of the Australian Meningioma Support Group and this is definitely worth a look.

The BTAA wants to ensure connection in the brain tumour community, and is taking the initiative to seed the formation of a National Brain Tumour patient collaborative group. For too long the many wonderful small, medium, and large brain tumour support groups and charities across the country, have worked in isolation in Australia. This has meant that services vary greatly across the country, and even across cities for brain tumour patients. The BTAA has established a project officer role, and moves are well underway with the various stakeholder groups to develop a collaborative group governance model that does not infringe on the current great work being done but does allow sharing and consultation. Thanks to Craig Cardinal who has worked to achieve this important initiative.

The BTAA represents Australian brain tumour patients in both government and research projects in many different areas. Diane Dunn has worked tirelessly to raise awareness in the Federal Parliament with her "Head to the Hill" initiative. COVID restrictions have so far prevented this from happening, but we are all hoping for a big event in November this year. Our members are regularly asked to be patient voices at funding and research meetings, and we regularly promote the many research programs being conducted.

The BTAA does not undertake large scale fundraising, but relies on many small generous groups and individuals who provide us with enough funds to remain operational. Please accept the thanks of all of our committee to these wonderful people.

All of our executive and committee are either patients or carers of brain tumours, or have lost someone to a brain tumour. None of our committee members and executive are paid and all work tirelessly to promote the interests of brain tumour patients. Many thanks to all of these people.

Catherine Hindson
Chair



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

Sienna Rossi's Story

COVER STORY

I had never thought of myself as a particularly interesting person.

At 18, I was diagnosed with a High grade neuroepithelial tumour - MN1 altered (BEND2/EWSR1 fusion variant).

During that time, I had many doctors tell me my tumour is interesting, rare, something they hadn't seen before. I didn't necessarily feel interesting just because I was somewhat of a medical mystery. I thought I had separated myself from my tumour, metaphorically and literally.

A friend recently asked me if she could interview me about my cancer journey for an assignment. Starting the interview, she asked me to introduce myself. I panicked, feeling like I was in front of thirty of my university peers doing an awkward icebreaker to start the semester. It was such a simple question and yet my mind blanked. Every thought, interest and hobby I had ever known simply disappeared from my mind.

Hi, my name is Sienna Rossi. I'm 19, but when I was 18, I was diagnosed with cancer.

Cancer was not something a person would typically bring up in an introduction or an icebreaker - I am sure it would make a room colder and less approachable.

Before I was diagnosed, I loved to read, binge-watch shows, line up for hours on end for concerts and obsess over celebrities. Yet, I had just reduced my identity to my name and my illness. I wanted to pause and scramble to clarify I am not identified by my illness! I am so much more than cancer! But nothing came out and I realised that for the sake of being interesting and relevant to my friend's assignment, I had been defined by my illness again.

In the course of the past 12 months, cancer has taken over my life. There were days when my body did not feel like my own; my veins a path for drugs to reach their destination, my skull a graveyard for an unwanted squatter and my hair on every surface of my house except for the right side of my head. Then there are days that almost feel normal and I am reminded of who I was before. Before the surgery. Before the diagnosis. Before radiation. Before chemotherapy. Before.

Every day I crave normalcy but I now know that my normal will be different, is different already. I have never craved the mundane until I faced the extraordinary; cancer.

As my treatment came to an end roughly 10 months after hospitalisation, I have tried as best as possible to resume a normal life. I have re-enrolled in university, bought concert tickets, gone out to eat in a restaurant, used public transport for city outings and hugged my friends without a mask. I have done as many mundane things that I could think of to regain my confidence, independence, personality and ultimately, my life. Amongst all of this, I still have routine scans and appointments (catalysing what every cancer patient knows as 'scanxiety') every two months as a constant reminder of what has happened and what could happen in the future. But after everything, I am trying to live a life that is no longer defined by cancer. I don't want to live as an interesting case study, I simply want to live as a normal 19-year-old teenager.

— Sienna Rossi



'A Guide to Caring for Cancer Carers'

Gabriella Rossi

This little title was coined by my beloved 18 year old daughter Sienna who at the beginning of the 2021 Sydney COVID-19 lockdowns, was diagnosed with a Rare Brain Tumour called 'High grade neuroepithelial tumour - MN1 altered (BEND2/EWSR1 fusion variant)'.

Recounting the past twelve months would be a long, agonising story filled with grief and emotion. A similar story for many people. So, instead, I have decided to retell the often omitted path of the 'Carer'.

I write with one goal today; drawing from my own personal experience, suggestions on some Do's and Don'ts of how to 'Care for a Cancer Carer'. Getting right to the point, I'll start with what NOT to do:

- **Don't ask 'How Are You?'.** Three simple words, a normal greeting in most circumstances, yet this sentiment would make me descend into a downward spiral of pain & annoyance. My daughter is battling cancer, how do you think I'm doing? So start with other ways to open a conversation & to reach out.

- **Unless you know for certain that the Carer and their family is religious, do not offer religious anecdotes or trite words of encouragement.** Saying 'God has only given Sienna what she can handle' is as exasperating as 'How are you?' and "Be strong", again the Carer doesn't want to be told how to act or feel. Pushing them to be positive invalidates their emotions. Hollow words really don't help in this situation.
 - **Don't ask a million questions.** Remember, this is a delicate subject and a sensitive time so unless the Carer (or patient) explicitly offers to explain or give details, do not ask.
 - **Don't get me wrong, flowers are lovely, but when they fill up every corner of the house and all die within a week, they start to seem like constant reminders of our unfortunate situation.** Instead use that money to donate for Brain Cancer research! (I'll touch on that a little more later.)
 - **Don't pour your own grief and worry onto the Carer.** Words like "I'm so sorry", pity and a sorrowful face when you see the Carer, is a constant reminder of the harrowing situation.
 - **Platitudes like "I wish I could do more" don't actually help** - Don't give the carer something else to think about or decide. There is always something useful which can be done. Waiting for my instructions was frustrating & simply exhausting. I needed those in my inner circle to 'steer the ship' on the mundane things whilst I was in fight mode for my child.
 - **Please don't pardon or excuse those who didn't reach out.** A common statement that drove me bonkers was "They just don't know what to say or do". One of the mannnnnny sleepless nights in distress I thought "Well how about they step out of their awkwardness and discomfort for just a moment and step into my agony". Reach out in your way but be mindful of the Carer & patients boundaries. Don't expect to be met at the door with a smile or a call or a hooray or thank you. Reach out because you want to genuinely offer support, not because you're obliged and expect a response in return.
Note, ACTIONS speak louder than words. What you can DO when caring for a Cancer Carer.
 - **Be Proactive!!** I cannot emphasise this enough. Stop asking 'What can I do?' The way to offer help is to just start doing what needs to be done. Communicate with close family & friends to rally an army together to offer various ways of support especially when treatment is taking place eg: make & share a Google Doc so that there's no double up on days in organising meals / pantry staple drop offs, detailing dietary requirements, time slots etc. Be mindful that healthy nutritious food aids in recovery during treatment. Do what works for the Carer & patient rather than what is convenient for your own agenda. Important note that if you can't fulfil a request from the Carer within a timely manner communicate so they are able to ask someone else.
 - **Fundraise or donate for cancer research through work, school, community etc.** Knowing that effort towards finding a cure gives the Carer & patient reassurance that their community is assisting in the fight! A suggestion to show your support is to screenshot the confirmation email of the donation or fundraiser, it will always be well received by Carer. You don't need to explicitly share the amount, but it lets the family know you've got their back in supporting the change for a better outcome for Brain cancer sufferers.
 - **Sending cards or postcards with sassy comical affirmations are a nice surprise to the usually mundane mail.** Share your spotify music playlist or movie recommendations as there's a lot of downtime in treatment
 - **Often, Carers are unable to work as they have to take care of their sick child/partner/parent and may have to drive far for appointments.** It's dreadfully awkward talking about money and the expense that is taking place. Some suggested items to send & share in the Google Doc are petrol vouchers, grocery vouchers or non-perishable pantry food staples to the door, healthy treats for the patient. Unexpectedly I had received a 'Dinner Ladies' voucher which for me was such a great idea & support especially as we were in lockdown.
 - **In the age of COVID-19, the patients (and therefore the Carers) are often suggested to remain in Isolation.** Arranging an activities package like puzzles, art supplies etc is a blessing when one has been holed up for 12 months. (Sienna was going crazy being with her parents every day for months on end). Spotify gift cards or Netflix gift cards are great suggestions and perhaps shared on the Google doc again not to double up on the same items.
 - **Research!** For multiple reasons: Although there are various types of Brain Cancers & outcomes, doing some research of your own to get a general understanding of the gravity, treatment regimen & expectations can be helpful so the Carer isn't on high rotation repeating and reliving the trauma. I wanted people to stop asking really dumb questions! It's also helpful sharing with Carers, relevant information like support groups, therapists and counsellors, or any new advancements in a cure, but always ask if they would like to receive it first. Whilst it's obvious that cancer patients will need support both during and after this ordeal, the trauma faced by Carers is often forgotten - help them out.
 - **LISTEN:** if the carer is venting, sometimes it's not for advice but to expel the trauma endured. Really listen to the details shared, as often close family & friends would ask over and over again about important details like medication or dietary requirements which had been previously discussed. It's very frustrating & draining having to continually repeat yourself.
- The path of a Cancer Carer is relentless. Some people will do and say stupid things even when you explicitly state your expectations. I feel a calm head & open heart is needed to support a Carer. I still struggle to interact on a social level, especially with family and friends that were absent during the worst 12 months of our life. But I've also become closer with so many people who were constantly doing research, cooking, folding paper cranes or texting silly photos to make us laugh. For every stupid or annoying act and comment, there were so many good people 'holding us up'. Whilst I wish this catastrophe never happened, it did fill my heart about the community, the tribe that is behind myself and my family.

BTAA's Elder Statesman Turns Eighty

Colleagues, supporters, family and friends recently gathered to celebrate BTAA elder statesman, Denis Strangman's eightieth birthday at a luncheon in Canberra.

Denis was one of the founders of the Brain Tumour Alliance Australia (BTAA) formerly Brain Tumour Australia (BTA), in 2003, as well as being instrumental in establishing the International Brain Tumour Alliance (IBTA) in 2005. Denis also held many executive and committee roles in the BTAA, and in later years and currently, Denis' wide ranging knowledge in all areas of brain tumour treatment has been an important resource for our organisation. Denis' intimate understanding of government, has allowed him to work to ensure that brain tumour patients are not forgotten in national policy and that important medications have been made available to all Australians with brain tumours.

Denis' story was shared at the luncheon in which his many and varied roles were featured. Denis worked in the Australian Public Service, and for sixteen years as a political advisor to Senator Brian Harradine. He was the Secretary and Board Member of the ACT Little Athletics Association and coached over 50 competitors in racewalking, as well as sprinting, hurdles and long jump. Denis was also actively involved in the Catholic Church and wrote many articles for their publications.

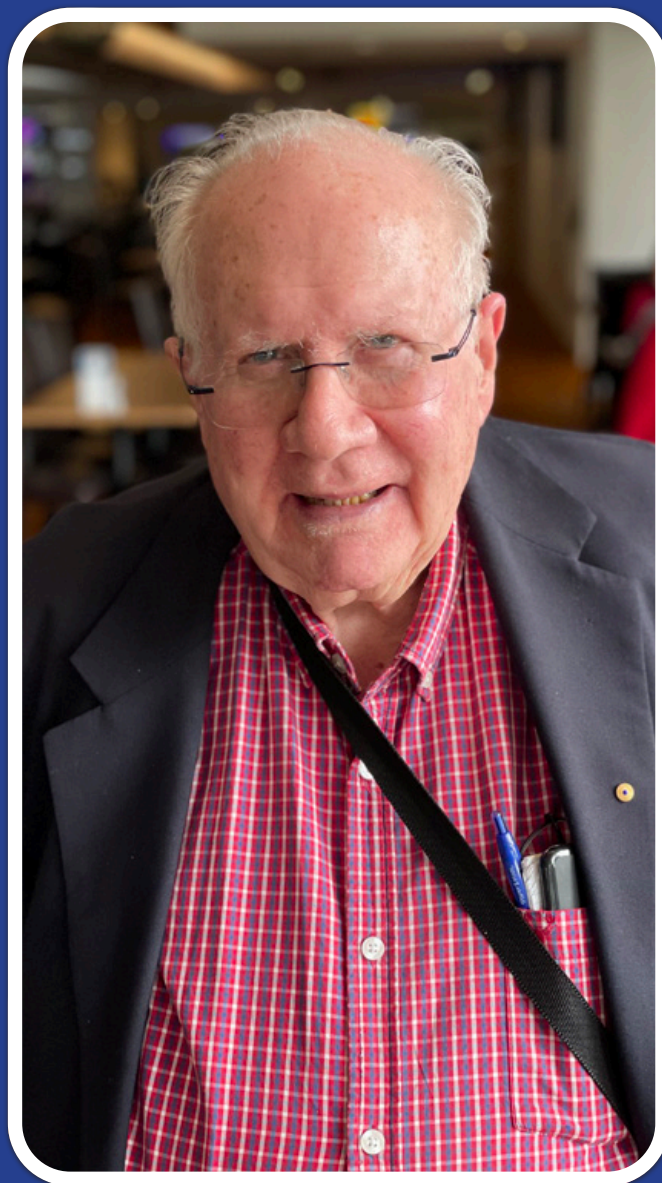
Below is an extract from Denis' writing about the founding of the BTAA.

In 2000 disaster struck. Marg (Denis' wife) was diagnosed with a malignant primary brain tumour.

I desperately wanted to meet up with someone who had travelled the same journey and I knew was up ahead of our family. Staff at one of the cancer wards at Canberra Hospital placed me in touch with Denis Argall and his wife Margaret who has been diagnosed with a similar brain tumour at about the same time. Denis had been Australian Ambassador to China and he had a different political approach to the Senator and I. I had also known him in the Parliamentary Library.

Following Marg's death in 2001 I and several other friends established Brain Tumour Australia (BTA) in 2003. I was on a steep learning curve and also got involved with cancer advocacy groups, mainly through Russell McGowan, who is also here today.

BTA received a grant from the Federal Health Department and I asked the official when he handed over the cheque "What should I do with this" and he replied "Just do what you have been doing. Unfortunately, there was a tussle for control of the organisation and myself and friends gave in to the rival group. They proved their incompetence and handed most of the grant back to the Department.



In 2005 I met up with a mother in the UK whose son also had a malignant brain tumour and we established the International Brain Tumour Alliance (IBTA). I was Chair and the woman, Kathy Oliver, was secretary. We ended up with a worldwide circulation of 11,000 of our yearly brain tumour magazine. I retired from that organisation in 2015, after being presented with a public service award from the 2000-strong Society of Neuro Oncology (SNO) in the USA. I once added up the trips I had made and I had visited 24 countries via 40 flights in promoting the IBTA and publicising the need for more recognition of brain tumours. In 2015 I was awarded an AM, sponsored, I suspect, by my friends in BTAA and the IBTA.

— Denis Strangman

The Brain Cancer Group Event Using Improved Molecular Analysis of Brain Cancer To Guide Future Therapy and Research



On the 10th of August The Brain Cancer Group (TBCG) hosted its 5th Brain Cancer Awareness Raising event at NSW Parliament House.

The Brain Cancer Group, Care2Cure (formerly Sydney Neuro-Oncology Group), was established in the year 2000. It is led by leading brain cancer specialists on the Royal North Shore Hospital Campus. The Group has established programmes under its 3 pillars of Research, Education and patient and carer Support.

This annual education event is open to the public and brings together patients, carers, brain cancer specialists, politicians and community leaders, to raise awareness of the challenges faced by brain cancer patients and families and update on progress of our programmes. This year's topic was "Using improved molecular analysis of brain cancer to guide future therapy and research". The event was hosted in association with Brain Tumour Alliance Australia (BTAA).

TBCG and BTAA have forged a strong partnership, bringing to the public and health professionals, informative education events, such as our recent Oligodendroglioma and Meningioma webinars. In October, TBCG will again sponsor BTAA's Patient forum which will take place at the beginning of the Co-operative Trial Group for Neuro-oncology (COGNO) conference in Brisbane.

Keynote speaker was Clinical Associate Professor Michael Buckland, a Senior Staff Specialist and the Head of the Department of Neuropathology at Royal Prince Alfred Hospital. He is the founder and Director of the Australian Sports Brain Bank, Co-Director of the Multiple Sclerosis Australia Brain Bank, and Head of the Molecular Neuropathology Program at the Brain & Mind Centre.

Second speaker was Dr Alexander Yuile, a Medical Oncologist/PhD Candidate with a keen interest in primary brain tumours. Dr Yuile gained his medical degree from the University of New England and is currently working in the oncology clinical trials unit at Royal North Shore Hospital.

He is currently enrolled in a PhD in primary brain tumours focussing on targeting molecular pathways as a treatment avenue.

Dr Jackie Yim, the third speaker, is a radiation therapist and holds a PhD in health economics titled,

"Economic implications of anxiety and depression in cancer care." He is passionate about research that seeks to improve patient outcomes and brings to the team his expertise in project management and analysing large datasets. Dr Yim has worked across public and private radiotherapy settings and in both, led the development and implementation of new clinical practices. He joined the TBCG clinical research team as a project manager in March 2021.

Our final speaker for the evening was Associate Professor Michael Back, Director of Radiation Oncology for the Northern Sydney Cancer Centre at Royal North Shore Hospital and Director of The Brain Cancer Group. He is also a visiting consultant in radiation oncology at the Central Coast Cancer Centre and for GenesisCare Private Centres across Sydney. He was appointed as an Honorary Consultant for Neurosurgery at the National Neuroscience Institute in Singapore. He subspecialises in Neuro-oncology with clinical and research interests in improving the outcome of patients managed for brain cancer through sophisticated tumour targeting and radiation therapy delivery.

The aim of the research program is to develop treatment protocols that can optimise the amount of radiation delivered to a brain tumour, whilst protecting the surrounding normal brain tissue. The benefits of this research is directly translated to the patients managed in daily practice in Northern Sydney. A/Prof Back has curated and leads The Brain Cancer Group's newest clinical research initiative, the Brain Cancer Databank which includes an Australasia first Imaging Laboratory.



During the evening, The Brain Cancer Group revealed its new branding and website, a project delivered by the talented team from Workhouse Visual Communications, represented on the night by Michael and Pat Kalucy and Neryl Press. TBCG was rebranded, creating a fresh new look which extends to a new, easy to navigate website.

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**The Brain
Cancer Group**

Dogs Get Agile For Brain Tumours

Dog lovers from the ACT Companion Dog Club recently got together to support one of their members who was diagnosed with a brain tumour, by conducting a mock agility trial.

The event called “Ace It!” was in support of Emma who was diagnosed with a Diffuse Leptomenigeal Glioneuronal Tumour and was keen to run her dog, Ace, in a trial. Emma and Ace trained hard for the event along with 27 other agile dogs. Emma has been training at the club for 4 years with Ace, a four year old Staffordshire Terrier, Cattle Dog cross in Agility and Rally. Although not technically a rescue dog he still is an RSPCA dog, acquired as a puppy. Emma is an active part of the Agility subcommittee. She also helps with clubs Flyball team despite not having a dog in the sport.

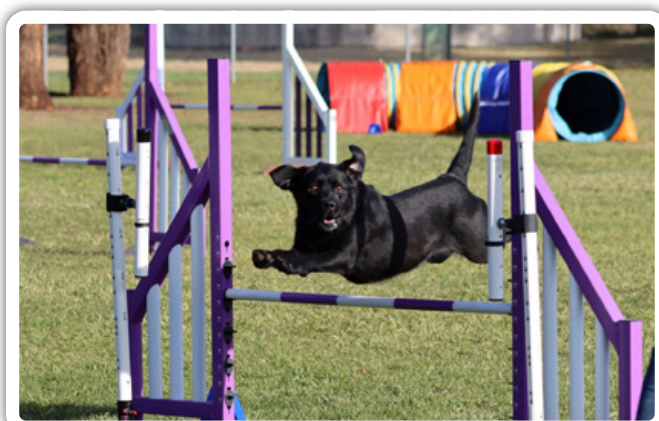
Dog agility is a dog sport in which a handler directs a dog through an obstacle course in a race for both time and accuracy. Dogs run off leash with no food or toys as incentives, and the handler can touch neither dog nor obstacles.

Jumping is a similar event but only has tunnels and various jumps as obstacles.

They are both essentially a team sport where you are in charge of the strategy and your dog is responsible for the athleticism.

The group are planning on holding our mock trial every year and setting up a perpetual shield trophy. All the funds raised were donated to Emma's chosen organisation and she chose BTAA as they have supported her and her family.

Many thanks to Kirstin Morris and the members of the ACT Companion Dog Club for organising this event and giving their time to judge and set up the course.



Nicola Scott Golf Day Success



The annual Nicola Scott fund raising event has once again been a great success raising in excess of \$10,000. Michael and Tracey Scott, who are the parents of the late Nicola Scott, mark the ten year anniversary of Nicolas's passing by organising a four person Ambrose Charity Fundraiser at the Sandy Gallop Golf Club in Ipswich. The funds are used by the Nicola Scott Educational Trust for its ongoing Educational Grant funding.

Nicola Christine Scott was born in Ipswich on Thursday, 25 July 1991. Nicola passed away peacefully in her sleep on Monday, 2 July 2012, just 23 days short of her 21st birthday. Nicola was the only child of Michael and Tracy Scott.

At 13 years of age, Nicola was diagnosed with a low grade (Oligodendroglioma) brain tumour on 20 May 2005, following four seizures within seven months.

Nicola loved the colour purple and butterflies, her bass cranked up, listening to club music, attending festivals, concerts, clubbing, camping, drifting - having a go at whatever task was put in front of her. Growing up, Nicola participated in Little Athletics and Karalee Swimming Club.

The Support Grant was set up in 2013 on the first anniversary of Nicola's passing. The foundation encourages and assists health professionals, new to brain tumour care, and experienced workers, to gain further knowledge by attending various conferences in Australia and overseas. These are the people on the "coal front" of brain tumour care. If you know of anyone in this industry who could benefit from the Grant, please share with them and have them contact the BTAAA for further information and how to apply.

The Nicola Scott Trust, through the BTA offers two types of scholarship:

Educational Grants - which are available to our financial members who are nurses and other allied health professionals, or researchers, with a particular interest in supporting people living with brain tumours.

- Grants are available to attend events like COGNO in Australia and SNO, ISPNO and ASNO internationally. Download the guidelines [here](#).
- Supporter Sponsorship Grants - which are available to our financial members who provide peer-to-peer support. e.g. those who run support groups, those who volunteer for the Cancer Connect Service, those who manage a dedicated online support page.
- Financial assistance is provided to enable our members to attend the BTAA National Summit, held in conjunction with COGNO. Grants are on a case by case basis and depend on the distance to be travelled, other income sources etc.

BTAA reimburses expenses up to \$1,200 for a national event or \$2,500 for an international event, upon presentation of receipts for travel, accommodation or registration. More money may be available at the discretion of the BTAA committee.





DIPG in Australia

Gerry Tye

Diffuse Intrinsic Pontine Glioma (DIPG) is a disease of the Central Nervous System (CNS) that is classified by WHO (World Health Organisation) as a DMG (Diffuse Midline Glioma).

DIPG is Diffuse within the Pons part of the Brainstem, an eloquent area that is inoperable, just think of sand in jelly where jelly is the normal neural tissue and the sand the tumour material. Hence our only hope is chemotherapy and molecular medicine.

DIPG is currently Terminal in Nature, that means that they will die sooner or later. The average survival rate post diagnosis is 9.5 months with some going on to 18 months to the rare unicorns of 2+ years. We lose ~30 DIPG children a year in Australia, that we know of. The medical pathway, until September 2022, was to have radiotherapy, dexamethasone, and go home and make memories until your child dies.

Neil Armstrong was an Astronaut, parent and the first person on the Moon. Sadly his daughter Karen Anne (Muffie) aged 2 and a half years old died within a few months from DIPG on 28th of January 1962, prior to his landing on the Moon in 1969.

Her treatment at the time was the standard radiotherapy that we have today. Muffie has a crater on the Moon named after her, thanks to her grieving father.

For myself the diagnosis and treatment has been the same here in Sydney Australia in 2012, where my 5 year old son Talin was diagnosed at Sydney Children's Hospital on the 11th of April 2012, had part of the standard radiotherapy and dexamethasone steroidal treatment, only to be sent off to die on the 17th of July 2012 at Bear Cottage Children's Hospice, 13 weeks later, in my arms.

Talin is a Live Cell Line at the CCIA (Children's Cancer Institute of Australia) under Dr's David Zeigler and Maria Tsoli.

Josephine Laura Dun was born to Dr's Matt and Phoebe Dun and sadly was diagnosed, February 2018 and died from DIPG 22 months later. Her father is a medical cancer researcher who specialised in leukaemia at the time, before his lab switched focus for Josie and her battle with DIPG.

But of course, Matt and Phoebe have not stopped in the Land of DIPG and have gone on to create RUNDIPG for the purpose of creating funding and research into this deadliest of diseases here in Australia with International Collaboration.

Additionally this includes a DIPG Clinical Trial that is just opening in September 2022 at Westmead Children's Hospital thanks to Matt and Team and the Pacific Paediatric Neuro-Oncology Consortium (PNOC). This involves usage of the agents ONC201 and Paxalisib and is supported by ANZCHOG (Australian & New Zealand Children's Haematology/Oncology Group), the Isabella and Marcus Foundation, the Robert Connor Dawes Clinical Trial Program, the Australian Brain Cancer Mission and the Wayne Francis Charitable Trust.

For me in 2012, it was a matter of a scrawling note on a bit of A4 paper at Sydney Children's Hospital (SCH) and the message to go home and make memories. There was No Hope, No Clinical Trials, No Resources on the Web that were significant in DIPG. While Talin was asleep I was up sitting on the stairs in SCH writing away a blog of memories of his journey at the time. Later on I would think that there must be other parents that would need this information as they were thrust into the uncertainty and dire timely nature of DIPG.

Again I searched on the web and found Paul Miller's group DIPG (Diffuse Intrinsic Pontine Glioma) Awareness for Family and Friends and became an Admin on the 3rd of April 2013 and have been so since, it encompasses 4,862 people.

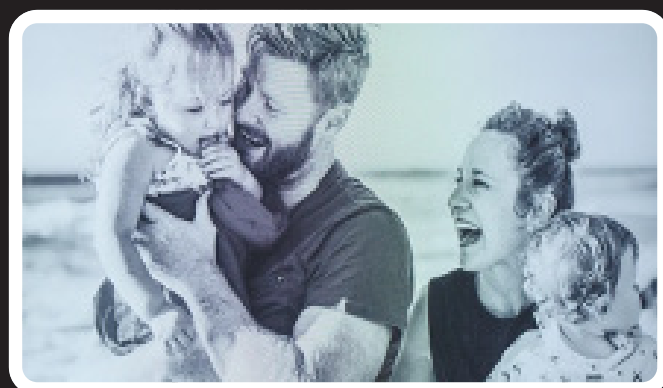
Due to the voracious demand for medical information in DIPG I created DIPG RESEARCH in 2014 to separate Support from Medical Information and it encompasses 3,716 people, including medical professionals, neurosurgeons, oncologists, nurse practitioners, stakeholders and parents.

DIPG had little media attention at the time and if it was mentioned it was under the banner of brain cancer if we were lucky. Of the 4% on average funding for childhood cancer, DIPG got basically no funding and is funded by parents, their charities and foundations with few complimentary government grants.

We have moved ahead over time and are now being more recognised as a high profile cause thanks to the work of Dr Matt Dun and team, with the help of foundations...

Additionally, we have many families that have donated priceless neural tissue for medical research at the various labs around Australia, including the CCIA.

My son Talin is one of them and is part of the foundation for the formation of the clinical trial by Dr's David Zeigler and Maria Tsoli using the drugs AMXT1501 and DFMO.



Brain Tumour Collaborative to provide a Cohesive Voice

Colleen Krestensen

Activity has commenced within the brain tumour support community to establish an Australian Brain Tumour Collaborative. Whilst it is early days, it is hoped that this Collaborative will aim to provide a cohesive and clear national voice on key issues of concern to Australians impacted by brain tumour, reflecting the shared views and experience of key organisations and experts in the sector. It is expected to have a particular focus on gaps in support and information for individuals, carers and families impacted by brain tumour.

Collaboratives of this nature have played an important role in other areas of health, where consumer groups, clinical services and researchers have joined together to work together to target particular needs at a national or local level and/or to raise awareness of particular issues. Collaboratives can act as a conduit for consistent, shared messaging and coordinated activity towards a common purpose through formalising partnerships and articulating agreed goals and objectives. Collaboratives involve a collection of organisations and/or individuals, through partnerships generally supported by some form of agreement or Memorandum of Understanding and clear governance frameworks.

There is already significant goodwill and considerable agreement amongst organisations and experts in the brain tumour sector on what works and what needs to change.

The Collaborative is intended to harness this goodwill and agreement. It is expected to identify a small number of priority areas, capture consensus on the problem and the way forward, and facilitate a clear, unified approach to information sharing and coordinated advocacy. The Collaborative will draw on the knowledge and expertise of a range of support, research and clinical service groups in the sector and the experience of consumers and carers who have been impacted by brain tumour.

The Collaborative will respect the autonomy of individual organisations, and complement other collaborative or cooperative activity underway in respect to research or clinical service provision. It will also be underpinned by a strong principle of shared ownership of the messaging and outcomes of the Collaboration.

BTAA is coordinating the early establishment of the Collaborative, and has appointed Colleen Krestensen as a temporary project coordinator to develop governance and other foundation documents through discussions and consultation with other organisations over the coming months. Further information about the Collaborative will be made available in future newsletters. If you would like more information about the Collaborative, please contact Colleen through BTAA.

It's **okay** to ask

Questions to ask your healthcare team about your **brain tumour** and treatment



The Supporting People with a Brain Tumour project is a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government.

Vietnamese | Tiếng Việt

Cứ hỏi **không sao cả!**

Những câu hỏi nên hỏi toán chăm sóc y tế của quý vị về vấn đề u não và điều trị



Dự án Supporting People with a Brain Tumour (Hỗ trợ Người Bị Bệnh U Não) là một chương trình *Supporting People with Cancer* (Hỗ trợ người bị bệnh ung thư) của Cancer Australia, được Chính phủ Úc tài trợ.

MHF MAGICAL EVENING

The ballroom of NEX, Newcastle was transformed into a winter wonderland on Saturday 27 August to celebrate the 6th Mark Hughes Foundation Magic Ball, the first since 2019!

The Mark Hughes Foundation (MHF) is a Non-Profit, Health Promotion Charity that Kirralee and Mark Hughes began in 2014, after he was diagnosed with brain cancer. They began the Foundation when they realised how underfunded brain cancer was in Australia in comparison to other cancers. The lack of funding meant very little research into treatments or cures for brain cancer and, as a result, not much has changed in the shocking brain cancer mortality rates over the past 30 years.

To date the Foundation has raised over \$24 million and funded; a Brain Cancer Biobank, Travel Grants, multiple research projects around Australia including three Fellowships and multiple Brain Cancer Care Coordinators. Amazing!

As 600 guests filled the room the night began with a bang! A drop curtain revealed three acrobats on stage in a giant water bowl performing to a string quartet! MC, Emma Lawrence, then started the formal proceedings and sat down with Mark and Kirralee for a chat about the foundations humble beginnings and how far we have come.

The room was electric when internationally acclaimed artists, Tap Dogs took the stage! This had everyone pumped and ready to raise money as the live and silent auctions took off.

The night finished up with the dance floor full and the announcement of an incredible **\$224,741.09** raised!!



Thanks to gold sponsors ScaffBuilt Solutions, AHA Hunter & Newcastle and The Man Shake as well as our Silver and Bronze sponsors, Corporate Partners and Beverage Partners. The Mark Hughes Foundation couldn't achieve what they do without you all, along with the generous people and businesses that donated prizes toward the evening's raffle and auction and the volunteers that gave up their time and everyone that contributed to the production on the evening!

Thank you to the guests and to those that bid at home, we are always overwhelmed by the support that our MHF Ball receives. This one felt that extra special after a few years off and we can't wait to do it all over again in 2023 – Save the Date for August 19th!!!



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Wendy's Story

I located the Brain Tumour Alliance Australia recently, fourteen years after I was first diagnosed with a tumour and would now like to share my story.

In October 2008 I was diagnosed with a large right non-malignant Petroclinoïd Meningioma. I was working full-time in a stressful job and a sole parent of a 14 yr old boy. To say I would never be the same again and my life would change forever is an understatement. I was shocked and traumatised by this news as I was fit, healthy and had no family history of brain tumours. One of my managers at my place of employment had died quite unexpectedly months earlier of a brain tumour and whilst his was malignant, I was terrified of my journey ahead. I reached out to the Cancer Council in South Australia for advice and maybe some counselling, but was told because my tumour was non-malignant, technically, I did not have cancer. My neurosurgeon was not aware of any support groups I could tap into in South Australia at this time.

In January 2009 I underwent a 13 hour craniotomy with no post-operative complications, however, there remained a residual enhancing lesion. The gaps for the surgery were huge and I had no choice but to sell my house. I had 3 months off work to recuperate and transitioned back to work, albeit quicker than I probably should have, due to pressure from my manager at the time. This same manager proceeded to bully and harass me in the workplace because of the illness. I refused to give in, give up or leave, and took "them" on. This was a really tough time.

In December 2012 a MRI showed residual enhancing lesion had increased in size, so in March 2013 I underwent 7 weeks of Stereotactic Radiation therapy in Randwick, New South Wales as South Australia did not offer this type of treatment at that time. This was my Neurosurgeon's recommendation. The treatment was at no cost to me, however several flights there and back and Hostel accommodation close to the hospital for 7 weeks, added up.



1. **Benign:** gentle and kindly.
Similar: kindly, warm-hearted, good-natured, friendly, warm
2. Medicine: (of a disease) not harmful in effect.
"a benign condition"

This was a very lonely and difficult journey for me. My specialist and treatment team were superb. Thankfully a couple of close female friends and my (by then) 20 year old son visited me for a few extended weekends.

I was very fortunate that someone in Adelaide gave me the name of a wonderful woman in Sydney (part of Cancer Council NSW) who ran a support group for brain tumour survivors and those undergoing treatment.

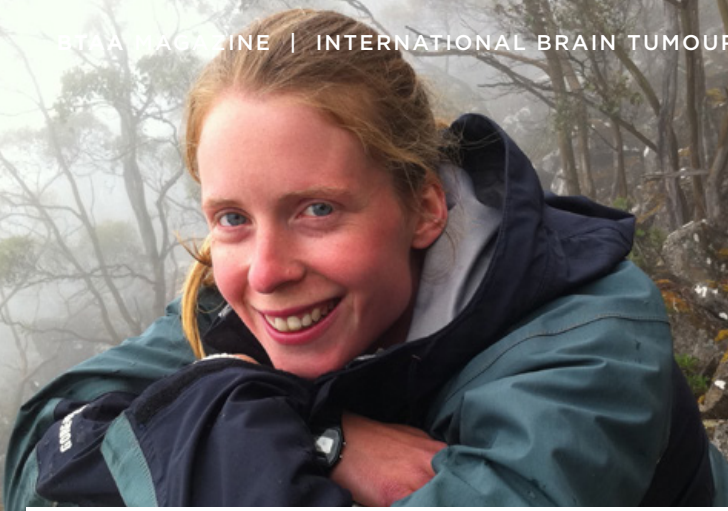
I got the courage to phone her and she very warmly and strongly encouraged me to be part of this group. I did join and what a wonderful and kind person she was, as technically as I was from South Australia, she did not have to do that. Once a week I would have to catch a bus to the location for a weekly BBQ. Other members of the group were NSW residents and the location was Cancer Council accommodation. I wasn't able to stay there as it was full. I often got a lift back to my accommodation in Randwick so I did not have to catch a bus or taxi at night.

Radiotherapy was successful. I do have some side effects such as double-vision, however, I'm very grateful I have been able to see my young son grow into a wonderful, resilient, hardworking man. The journey was very tough on him too. He did not get a lot of family support whilst I was in Randwick having treatment.

In August 2013 I accepted a redundancy from the organisation I had been working for, but continued working, undertaking many and varied contract positions including one at SA Cancer Council (ironic don't you think?).

I retired from the workforce two and a half years ago, and I am now a 67 year old retired female, on an Aged Pension living alone in Adelaide. My son turned 30 and became engaged on 16 May this year. I'm due for my biannual MRI and Neurosurgeon appointment in June.

Wendy



The Gifts of Survival

Kate Bown

Ten big beautiful years.

That's a pretty good score for a girl with a rare posterior fossa brain tumour. For me, it also marks a marriage milestone. The traditional tenth wedding anniversary gift is aluminium. Or silver earrings, like the ones my husband gave me. But what are the gifts of surviving a brain tumour for a decade? What have I learned from my journey?

I have wanted to write my story for BTAA for many years but have struggled with how to write a story of survival. What would I say about the ten years that have past, without feeling awkward, vulnerable and ashamed of still being here. But when I began with a question - what have I learned? - I finally felt ready to share my story.

Like so many of you, my story began with loss and grief; a turbulence of disbelief, fury, sadness and 'if only'. But as time passed and I began to recover, I learned that sometimes, feelings of loss can surrender to love, gratitude and courage: the gifts of survival.

In the spring of 2012, I woke with a headache that wouldn't go away. I was 27 then and newly married, with the world at my feet. How quickly life can turn. Over the following months, I had many visits to my GP, but it wasn't until I began to lose my balance that we knew something was wrong. I had an MRI scan and to our horror it showed a large mass in my brain. I felt like I had lost everything. My husband and I escaped to our local Mountain. We sat atop a cliff, held each other and cried. Two days later I was on an operating table saying goodbye to all that I knew.

Brain surgery removed most of the tumour and I received a hopeful diagnosis of a Grade 1, Rosette-forming glioneuronal tumour of the fourth ventricle (RGNT). A long name for a tumour that is extremely rare. I loved roses, but that morning I vowed I would never grow them in my garden.

My recovery was challenging. The surgery and steroid treatment injured my cranial nerves resulting in bilateral double-vision and a bell's palsy. I also had difficulties with walking, balance and coordination, fatigue, and insomnia. My future was uncertain. Illness was isolating. But it was the loss of my smile that rattled me.

My husband worked two jobs, anaesthetist and carer. I was 'queen of the house' and my kitten, Snowball, was princess.

What a sight I must have been shuffling along the hallway with a walking-frame and kitten in tow; a bumbag of medical accessories and an eye-patch.

As the months passed I learned to walk independently and to smile, although my double-vision remained. Humour came to our rescue. I joked I had two husbands. And when I started to feel energetic I set up the exercise bike and pedalled in fluorescent lycra to ABBA. My husband and I erupt in laughter when we remember. But there were 'dark days' too, when I wished I could dissolve and days when I smouldered, breathing my frustration on others.

In the end it was love that rescued us. Despite my wonky eyes, wobbly walk and ridiculous antics, my family loved me. So, I began to make peace with myself and my brain tumour journey. And there was joy, when I learned to look beyond what I had lost to all that I had gained. I found happiness in a cup of tea and 'snail mail' from a friend. I began to practice gratitude.

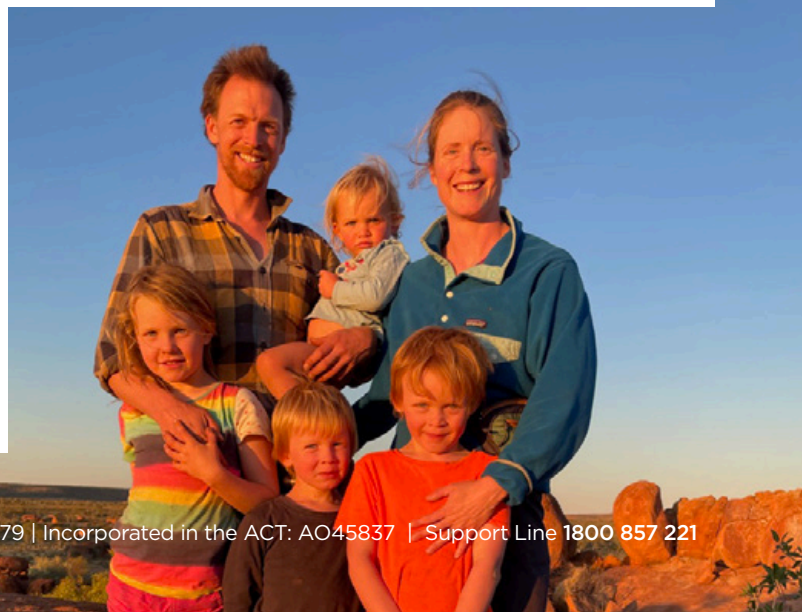
And then, seven months into my recovery, we received the most wonderful news. I was pregnant and in April 2014, our first child was born. The turmoils of illness gradually faded and were replaced with the joys and responsibilities of motherhood. Three more children arrived and time has flown - as a happy bustle of chaos and adventure.

I know I am lucky to have four precious children. They ground me in the here and now and give me the strength to face whatever my future may bring. Regular MRI scans and peripheral double vision are all that reminds me of the residual tumour in my brain - my little flair.

I still worry about the future, if my tumour were to grow again. But I am not the same person I was before my brain tumour journey. I am more resilient and courageous. I try to live presently, love generously and celebrate life.

The day before my last MRI scan, I noticed my thoughts beginning to unravel, to wonder, 'What if?' I cried. Then I walked out into our garden and smiled at all that my husband and I had grown together: four children, a home, the odd rose or two.

Loss will always be part of the tapestry of life. As time passes, I will try to remember the lessons that I learned all those years ago. To grieve honestly and patiently. To love deeply. To be grateful for what I have and to persevere when I am set adrift. With time, loss can give the gifts of love, gratitude and courage. An internal compass to navigate the journey of life.



Brain Tumours and COVID

International Research Shows No Major Side Effects of COVID Vaccines

A major international research project conducted in conjunction with the International Brain Tumour Alliance, with 965 respondents from 42 countries, has revealed no major side effects for brain tumour patients who have taken the COVID vaccines.

As the COVID-19 pandemic continues to unfold, the advent of multiple approved vaccines has led to a milestone in the fight against the virus. While vaccination rates and side effects are well established in the general population, these were largely unknown in patients with brain tumours. The purpose of this study was to determine if brain tumour patients and their caregivers have received a COVID-19 vaccine, and explore their thoughts and opinions on these vaccines.

An anonymous 31-question online survey available in 8 languages was conducted from June 30, 2021 to August 31, 2021. The survey was open to adult brain tumour patients over the age of 18 and included both categorical and open-ended questions.

Examples of the types of questions in the survey are shown below:

Question	Number / %
At the time of receiving your first and/or second COVID-19 vaccination were you on active treatment for your brain tumour?	696 (72.1)
If you were on active treatment for your brain tumour when you received your first and/or second COVID-19 vaccination, what treatment was this (please select all that apply)?	614 (63.6)
If your treatment plan for a brain tumour has changed because you received a COVID-19 vaccination, please explain how this has changed.	603 (62.5)
If you experienced any side effects from your first COVID-19 vaccination, please tell us what they were—you may choose as many of the below options as you wish. If you have not received a first COVID-19 vaccination, please choose "Not applicable."	692 (71.7)
If you experienced any side effects from your second COVID-19 vaccination, please tell us what they were—you may choose as many of the below options as you wish. If you have not received a second COVID-19 vaccination, please choose "Not applicable."	687 (71.2)
Do you feel that you have received enough information about COVID-19 vaccinations?	697 (72.2)
Do you have any concerns about the COVID-19 vaccine programme in your country (for example distribution, equal access, timing between doses, safety, etc)?	695 (72)

A total of 965 unique surveys were completed from 42 countries. The vast majority of both brain tumour patients and their caregivers have been vaccinated against COVID-19 (84.5% and 89.9%, respectively). No patient reported serious adverse events from any vaccine. Less than 10% of patients decided against receiving a vaccination against COVID-19, with the most common reason being concerns over the safety of the vaccine. Patients wanted more specific information on how COVID-19 vaccines might impact their future brain tumour treatment.

The BTAA worked with the IBTA to ensure that Australian patients and caregivers had their say in the survey.

Glioblastoma (GBM) was the most common brain tumour diagnosis at 24.6% (N = 208), followed by meningioma at 18.2% (N = 154) and astrocytoma at 12.7% (N = 107). Low-grade gliomas (grades 1 and 2) accounted for 38.7% (N = 327) of patients, while high-grade gliomas (grades 3 and 4) accounted for 43.9% (N = 371) with 22.4% (N = 189) unsure of the grade of their tumour.

Three key points were concluded from the study:

- **The majority of brain tumour patients and their caregivers have received COVID-19 vaccinations.**
- **No major vaccination side effects were reported in this group.**
- **Patients want more specific information on how COVID-19 vaccines might impact their future care.**

The full report, including a full statistical analysis of all results and detailed conclusions can be viewed in Neuro-Oncology Advances here: <https://academic.oup.com/noa/article/4/1/vdac063/6578659>

Congratulations to the authors and the IBTA for this important study;

Mathew R Voisin, Kathy Oliver, Stuart Farrimond, Tess Chee, Philip O'Halloran, Martin Glas, International Brain Tumour Alliance (IBTA) Senior Advisors, Gelareh Zadeh

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NEED SUPPORT NOW?

PHONE 1800 857 221



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

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

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

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

Email btaa@shout.org.au

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