BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

Brain Tumour Awareness
BTAA.ORG.AU
1800 857 221

MAY 2022
BTAA.ORG.AU

Wear a hat for a day to Go Grey In MAY!

INSIDE THIS EDITION

- GBM AGILE TRIAL
- MAVERICK GRIEF – IGNITING A GLOBAL GRIEF REVOLUTION FOR CHANGE
- PATIENT STORIES
- ROGUE WAVE RAISES AWARENESS DESPITE SETBACK

THIS MAGAZINE WAS PRODUCED WITH THE ASSISTANCE OF DONATIONS

ABN 97 733 801 179 Incorporated in the ACT: AO45837 Freecall number 1800 857 221

NEED SUPPORT NOW?

PHONE 1800 857 221

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

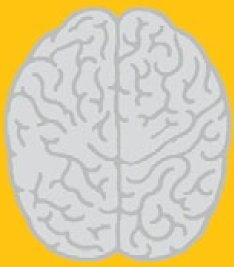
To talk with experienced caregivers, call BTAA on the Support number:
1800 857 221, and see the support groups available in your local area at
www.btaa.org.au – look for support organisations.

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



NRF
NeuroSurgical Research Foundation

NeuroSurgical Research Foundation

‘Go Grey In May Presentations’

Every Tuesday at 1 pm in May

Register www.nrf.com.au/events/go-grey-in-may

Brain Tumour Research SA

LETTER FROM THE CHAIR

Greetings to all in 2022. Unfortunately, Covid has continued to impact on many, however, thankfully, the effects of the disease are waning and we are learning to live with it in our lives.

BTAA is continuing to progress the National Brain Tumour Collaborative with our National Brain Tumour stakeholder/partners. To progress to the next level, we are looking to employ a part-time Executive Officer/Brain Tumour Collaborative Project Lead. The position will have limited tenure, however we anticipate approximately 20 hours per week over the initial period. This person will be responsible for liaising with all stakeholders, formulation of heads of agreement, and writing policy etc. The role will advertised and will attract appropriate remuneration. The role could well suit someone who has perhaps retired or similar, but who is looking to utilise their skills in a constructive, value adding way. If you are interested or would like to find out more, please ring me on 0412041245

In the past year three virtual forums were held, by the **Brain Cancer Group**, **Care2Cure** and **BTAA.**

The first session was a **Meningioma Educational Forum**. The second an **Oligodendroglioma Information Day**. The third was a **Patient education & Support Forum** held in conjunction with Cooperative Trials Group for Neuro-Oncology (**COGNO**). Their Annual Scientific Meeting and all sessions are available on our website. A huge thank you to the doctors who gave of their time for these sessions. The information delivered is so valuable to old and newly diagnosed patients and their families.

This year during "Go Grey in May", **Adelaide's Neurosurgical Research Foundation (NRF)**, are holding five Virtual sessions to raise awareness of Brain Tumour www.nrf.com.au/events/go-grey-in-may at 1pm on Tuesdays during the month.

The **Mark Hughes Foundation** is holding its 5th Annual Brain Cancer Forum on Friday May 20 at Souths League Club, Merewether. To register HNELHD-BrainCCC@health.nsw.gov.au or 0417 819 547

The Cooperative Trials Group for Neuro-Oncology (**COGNO**), will be holding their **Annual Scientific Meeting**. This year from Sunday 16th to Tuesday 18th Oct 2022. On Sunday there will be a **Patient education & Support Forum**. Additional information on topics and speakers will be forwarded to our subscribers when confirmed.

Our organisation is run exclusively by volunteers. By the time you read this magazine, our AGM will have taken place with a new executive elected. I would like to extend a big thank you to the outgoing committee for their dedication and commitment to BTAA.

We are always in need of more volunteers in all states to spread the word about the support available through BTAA. If you are interested in helping and /or being involved, I would love to hear from you chair@btaa.org.au.

I wish everyone: patients, carers, families, doctors, nurses, health care workers, brain tumour researchers, and brain tumour support groups a happy and healthy 2022, as we emerge from the pandemic.

Catherine Hindson
Chair

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

Hunter Brain Cancer Forum

MARK HUGHES FOUNDATION

Friday 20 May 2022

Proudly supported by the Mark Hughes Foundation

You are invited to attend the fifth Annual Hunter Brain Cancer Forum. Please contact Sharyn on 02 4037 7400 or enquiries@markhughesfoundation.com.au to RSVP.

When: Friday 20th May
Where: Souths Leagues Club Merewether
Cost: FREE
Food: Morning tea & lunch will be provided

Wear A Hat for a Day to GO GREY IN MAY

During Brain Tumour Awareness Month, Go Grey in May, we are asking groups across Australia to ‘Wear A Hat For A Day For BTAA’, to raise awareness and shine a light on the impact of brain tumours on patients, their families, and carers.

BTAA is encouraging everyone to take part in our event which will help increase awareness and bring much needed attention to fight against this devastating disease. All funds raised will enable the committed team at BTAA to continue providing support to brain tumour patients across Australia, including our 24/7 Free call support helpline (1800 857 221 - available in Australia only).

Our hope is that this event will become a nationally important fundraising and awareness event that everyone across Australia can support every year.

Choose a day that suits your group during this coming Brain Tumour Awareness Month in May and register your event here: **https://btaa.org.au/help-information/fundraise**

If you have a great photo of your event, we would love to you to share it with us via our email address and we will display the photo on our website. Let us know some details about your group, class or office so we can thank you for getting involved.

Please get in touch if you have any enquires, questions or concerns by contacting us by email enquiries@btaa.org.au or call us on 1800 857 221.

Wear A Hat for A Day for BTAA

HOW YOU CAN GET INVOLVED …

At home, school or community…

Get together as a family and fundraise at home or share the fun with friends and relatives, together or online!

Host a hat-themed games night with all your friends and ask them to donate to attend

Go virtual with a hat Zoom quiz – share it on your social media pages and try to get all your friends, family and colleagues to join in

Organise a sponsored activity, like a 5k or 10k walk or run wearing your most spectacular hat, and ask everyone to donate to support you

Share your hat selfies on social media – let everyone know you are taking part in #WearAHatDay and ask them to join in too

At Work…

Have fun at work and get all your colleagues involved. Boost the team spirit whilst raising awareness and help people affected by brain tumours.

Ask your colleagues to wear their best hats for all their Teams or Zoom meetings on the day

Host a hat-themed morning tea at the office and ask everyone to donate to sample the delicious treats

Plan some office games themed around hats

Hold a competition to see who can create the craziest hat out of only materials you can find in the office or at your desk

On social media…

USE THESE HASTAGS TO PROMOTE YOUR INVOLEMENT ON SOCIAL MEDIA

#BTAA
#GreyInMay
#BrainTumourAwarenessMonth
#HatForADayForBTAA

BTAA WOULD LIKE TO THANK YOU FOR SUPPORTING OUR ORGANISATION.

SAVE THE DATE!

COGNO
COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

For more information go to
www.cogno.org.au

Cooperative Trials Group for Neuron-Oncology

14th COGNO Annual Scientific Meeting: Reconnecting Neuro-Oncology

Co-Convenors, Dr Ben Chua and Dr Hamish Alexander, along with the organising committee are busy planning for our 2022 ASM. Save the date and stay posted for updates.

Sunday 16th – Tuesday 18th October 2022
Brisbane Queensland Australia

GBM AGILE Trial

The Cure Brain Cancer Foundation (CBCF), has announced a partnership with the Global Coalition for Adaptive Research (GCAR) to bring a revolutionary, first of its kind clinical trial for patients with glioblastoma (GBM) to Australia. GBM is a highly aggressive and fast-growing form of cancer. GBM AGILE (Glioblastoma Adaptive Global Innovative Learning Environment - NCT03970447) is designed to rapidly evaluate new therapies and connect patients with global research expertise.

GBM is the most common and deadly primary brain cancer in adults. It is highly aggressive and fast-growing, with an average survival rate of 15 months. Currently, only 5% of people with GBM survive 5-years post diagnosis. Standard treatments for GBM patients haven't changed in over 30 years.

Cure Brain Cancer Foundation's investment of AUD7.95 million will support the infrastructure build in Australia to allow for patients with glioblastoma to have access to this innovative trial program. It is expected that approximately 50 patients per year will participate in this effort, with infrastructure support from CBCF through the first 3 years.

Whilst traditional clinical trials are slow and take several years to evaluate a single drug, GBM AGILE accelerates the pace at which new treatments are tested for brain cancer, and represents an extremely efficient way to find better treatments for GBM. This trial delivers not just hope, but real action for the 95% of people with GBM who will not survive 5-years post diagnosis.

Cure Brain Cancer Foundation was one of the original seed-funders of GBM AGILE with an AUD1 million contribution in 2013. Now, GBM AGILE is recruiting patients globally, with leadership for GBM AGILE also serving as members of CBCF's Scientific Advisory Committee. With the recent commitment of funding by CBCF, CBCF will contribute the largest single investment by a foundation with AUD7.95 million in support. This will fund the establishment of trial sites in Australia and enable patients in Australia with GBM to gain access to new potentially beneficial treatments through this adaptive clinical trial program.

Brain cancer survival rates are low and have hardly changed for 30 years, despite significant increases in survival for other types of cancer. For instance, the five-year survival rate of prostate cancer has increased from 60 per cent to over 90 per cent, and breast cancer has increased 72 per cent to over 90 per cent. The survival rate for brain cancer has increased from 21.2 per cent in 1986, to only 22.3 percent today.

GBM AGILE is a global collaboration, connecting Australia with leading global researchers and scientific experts.

Find out more about GBM AGILE at www.gcaresearch.org/gbm-agile/about and Cure Brain Cancer Foundation at www.curebraincancer.org.au.

About Cure Brain Cancer Foundation

Cure Brain Cancer Foundation is an Australian-based organisation, who is working globally to rapidly improve brain cancer survival. The Foundation's mission is to unite the community and rapidly increase brain cancer survival, improving quality of life for people impacted by the disease, with a vision to ultimately find a cure for brain cancer.

To learn more about Cure Brain Cancer Foundation, visit www.curebraincancer.org.au or follow on social media: @curebraincancer

Information for patients

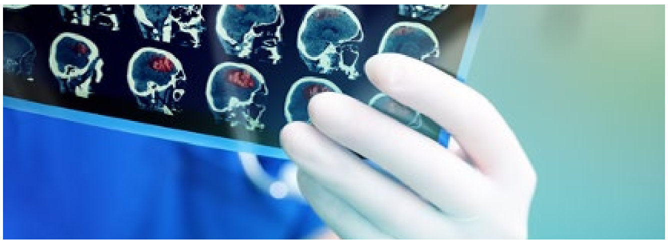
If patients are interested in participating in a clinical trial, such as GBM AGILE, they should speak to their doctor. They will be able to advise you on your eligibility and can recommend studies available to you. Remember that participating in research is a voluntary decision, and we encourage patients to consider the pros and cons of participating in a clinical trial. You can find out more on clinical trials via the Cure Brain Cancer website.

Cure Brain Cancer Foundation

GBM AGILE

is coming to Australia, thanks to an $8 million investment by Cure Brain Cancer Foundation.

A world-first global adaptive clinical trial; a revolutionary new way of testing and developing brain cancer treatments.



Maverick grief -

Igniting a global grief revolution for change

Jennifer Donohoe
Grieving Mother, (Bachelor of Business - Communications, RN)

One of the greatest travesties of our time, is the avoidance of grieving parents and siblings along with the medicalising and pathologizing of grief. I am beyond shocked by what we have endured in the community following the passing of our son and I see no sense or value in sweeping this issue under the carpet.

Our son passed at just 12 years of age. Sam did not "lose his battle" with the brain tumour as per the predictable cliché that is indoctrinated in this society. Sam continued his refreshing sense of wonder of life and lived with his life brain tumour as he did his life before diagnosis - with his usual fearless sense of adventure, love, loyalty, dignity, spirit, humour and grace. His impact unforgettable and eternal.

A diagnosis of brain cancer brought to light the gravest injustice that a child's life is not sacrosanct and above politics in this country. By not committing the significant and sustained, long term funding it requires to alter a fatal prognosis, unchanged for half a century, the Australian government should be held to account for the deaths of over a busload of children in this country, shattering thousands of lives Every. Single. Year. This will not change, unless there is lobbying of governments to commit to the significant, sustained funding for research, and appointing an independent watchdog to ensure that continuity of funding is protected.

The token gesture that is the current funding for research, has brought our shattered hearts, our shattered lives to this point. In trying to survive the death of our son, we have encountered a level of what can only be called out as discrimination and prejudice in our society toward parental grief.

Prior to our tragedy, we had good friends and a healthy network. However, in the face of the unspoken tragedy of the death of our child, we were maligned - suddenly by some, and a gradual, painful regression by others. As most grieving parents will attest, while you do all you can to survive each day, the impact of avoidance from those you trusted is the second wave of utter trauma. How much onslaught of pain can we survive? I have seen a few speakers on TED X speak from the heart on this, but essentially communities have no idea of the existence or magnitude of this issue. Many drastically underestimate the impact of their actions on grieving families. What astounds me is the inability of others to simply apologise if they hurt you, which given the stress and sorrow - will inevitably happen. Unless we dutifully accept sympathy card style of responses and speak no further of our son – we are abandoned.

This lack of care can impact by resulting in the feeling of invalidation of our grief, which can cause a catastrophic downward spiral. The discrimination, isolation and deep misunderstanding of grieving parents and families IS a vital issue and I stand in the courage of my conviction to do what I can to bring this into the public arena. Grieving parents are the only 'experts' on their own grief.

Grief is not a mental health condition. Grief is not an ailment to 'recover' from. Grief when your child dies does not travel through an upward trajectory to a definitive end (that belief is what is convenient for others), Grief IS love. How we manage to survive becomes ours to manage and what works one day, may not work the next. Others must resist the urge to give unsolicited advice or 'fix' what can never be 'fixed'. Everyone wants the person back before their child died. That will never happen. And this is what many who love you, do not accept. Those who want your grief to 'end' only serve to minimise or diminish the love we have for our children. What others say, and what a grieving parent hears, can be so different.

How you grieve is how you love – utterly on your own terms. You don't need to defend or validate how you continue to love your child who is not physically here on this earth. Others whose children are physically here, are not expected to justify how they love them.

There are structured organisations or grief support groups, however they are not for everyone, and from my experience it feels that it is a case of preaching to the converted. It is society that needs to get these messages. There is little out there to raise awareness of the crushing impact others can have on parents and siblings who live with children with cancer and those who are grieving.

It must start – and it has to continue so a genuine change of mindset can start to shift and impact of awareness, gain traction.

Parents who have children with brain cancer and those parents who grieve, are simply among the mightiest in our society for what they endure, and they deserve the utmost respect from others. What is currently trotted out by media and organisations needs an almighty pushback. What it takes to survive each day for us, is the epitome of what is humanity. What is dignity. What is respect. What is love.

We must hang on. We must become revolutionaries of truth to achieve genuine understanding from our families, friends and communities for what we endure and how they can support. I welcome all enquiries or for anyone who wishes to contact me through www.maverickgrief.com.

BTAA Social Media Now An Important Link For Brain Tumour Patients

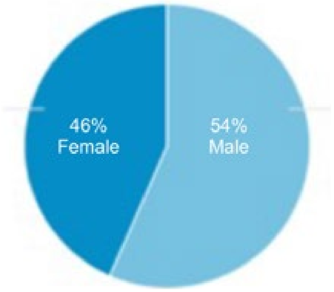
Members of the BTAA committee have been working hard to improve the outreach of our website and social media platforms over the past few years and this has paid off with significant increases in traffic on these channels. Our website, Facebook, Twitter, Instagram, Linkedin, and Youtube applications have all shown improvement.

The BTAA website was reconstructed in 2019 to give a fresh look and improved and up to date access to a huge range of resources and events across Australia and around the world. Given that brain tumours remain in the rare cancers group, the number of visitors each month indicate that we are able to serve a significant number of new patients and carers. Of interest is that it seems the website is the preferred destination for males and that a significant number of visitors come from overseas countries.

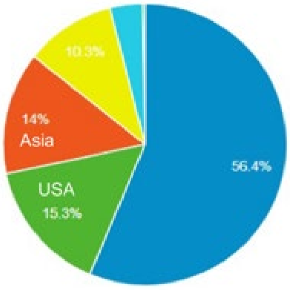
Insights include:

- 1.2k unique visitors to btaa.org.au during March, an increase of 15% compared with February
- 84% of all users are new visitors to the site indicating we are reaching new people affected by brain tumours
- The home page and resources/support pages are top destinations for users
- Google accounts for majority of referrals 42%; Direct referrals 33%; Social media increased to 17%
- 54% of website visitors are male, compared to only 18% of BTAA social media followers being male
- 56% of all visitors this month were based in Australia, 15% in US, 14% in Asia, 10% in Europe

Visitor gender

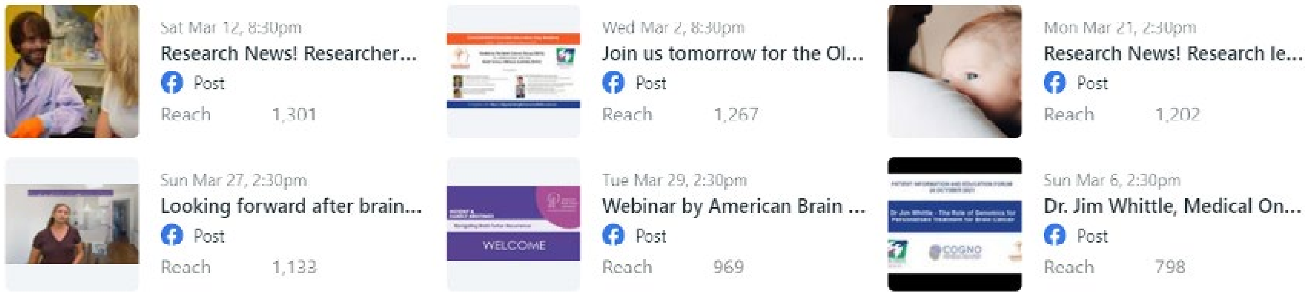


Visitor location



Facebook

Our Facebook page has also increased its following. Members especially like recent research posts and information about significant events such as patient education days and forums. Patient stories were also very popular and often shared. Some examples of the most popular posts are shown below.



Sat Mar 12, 8:30pm
Research News! Researcher...
Post
Reach 1,301

Wed Mar 2, 8:30pm
Join us tomorrow for the Ol...
Post
Reach 1,267

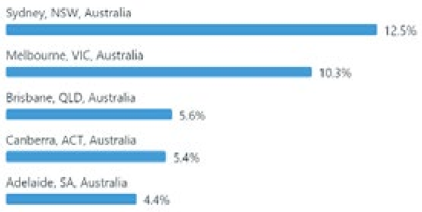
Mon Mar 21, 2:30pm
Research News! Research le...
Post
Reach 1,202

Sun Mar 27, 2:30pm
Looking forward after brain...
Post
Reach 1,133

Tue Mar 29, 2:30pm
Webinar by American Brain ...
Post
Reach 969

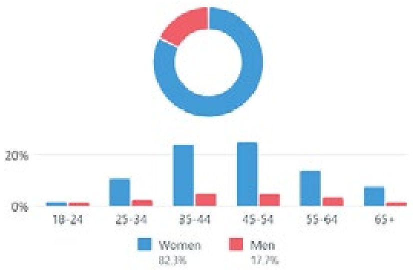
Sun Mar 6, 2:30pm
Dr. Jim Whittle, Medical On...
Post
Reach 798

Top Cities Facebook



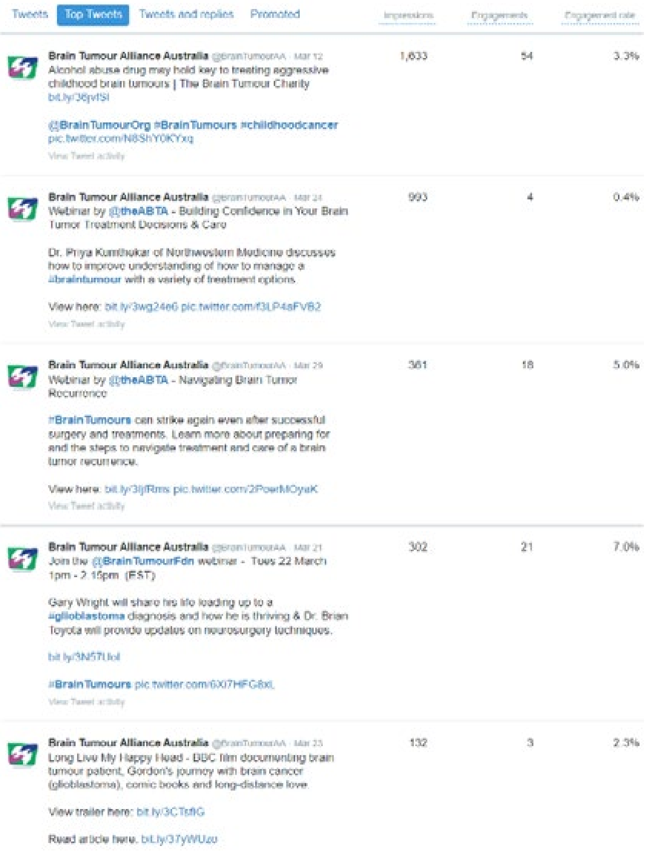
Top Countries Facebook

Gender Facebook



Twitter

Our social media team has also been busy activating our Twitter account. On Twitter our educational video and webinar links are very popular. Some of the post with the greatest response is shown below:



	Impressions	Engagements	Engagement rate
Brain Tumour Alliance Australia @BrainTumourAA · Mar 12 Alcohol abuse drug may hold key to treating aggressive childhood brain tumours | The Brain Tumour Charity bit.ly/36jvfSl @BrainTumourOrg #BrainTumours #childhoodcancer pic.twitter.com/N8ShY0KYxq View Tweet activity	1,633	54	3.3%
Brain Tumour Alliance Australia @BrainTumourAA · Mar 24 Webinar by @theABTA - Building Confidence in Your Brain Tumor Treatment Decisions & Care Dr. Priya Kumthekar of Northwestern Medicine discusses how to improve understanding of how to manage a #braintumour with a variety of treatment options. View here: bit.ly/3wg24eG pic.twitter.com/f3LP4aFVB2 View Tweet activity	993	4	0.4%
Brain Tumour Alliance Australia @BrainTumourAA · Mar 29 Webinar by @theABTA - Navigating Brain Tumor Recurrence #BrainTumours can strike again even after successful surgery and treatments. Learn more about preparing for and the steps to navigate treatment and care of a brain tumor recurrence. View here: bit.ly/3ijfRms pic.twitter.com/2PoeMOyaK View Tweet activity	361	18	5.0%
Brain Tumour Alliance Australia @BrainTumourAA · Mar 21 Join the @BrainTumourFdn webinar - Tues 22 March 1pm - 2.15pm (EST) Gary Wright will share his life leading up to a #glioblastoma diagnosis and how he is thriving & Dr. Brian Toyota will provide updates on neurosurgery techniques. bit.ly/3N57Ukl #BrainTumours pic.twitter.com/6X07HFG8xL View Tweet activity	302	21	7.0%
Brain Tumour Alliance Australia @BrainTumourAA · Mar 23 Long Live My Happy Head - BBC film documenting brain tumour patient, Gordon's journey with brain cancer (glioblastoma), comic books and long-distance love. View trailer here: bit.ly/3CTtflG Read article here. bit.ly/37yWUzo	132	3	2.3%

YouTube

The BTAA Youtube channel now provides a direct link to recording of our own patient education and support forums as well as multilingual support materials.

Behind the scenes

Special thanks must go to our very hard working committee members who have worked tirelessly to develop these services and to maintain them with relevant and current information. Peter Ramstadius worked intensively for a number of years to develop the current website and still contributes daily. Amanda Griffin and Diane Dunn have devoted themselves to improving and modernising our social media presence, and are our main contributors.

Diane Dunn

Secretary

In November 2016 I received a diagnosis of Grade 2 oligodendroglioma in my right parietal lobe and was advised it was inoperable. In common with most brain tumour patients, I was completely blindsided by this unexpected diagnosis. Prior to this, I was a very fit 54- year-old - vegetarian since 18, a non-smoker, and a non-drinker.

As a result of my diagnosis, I lost my small business - I was the sole owner/operator of a boutique bakery and, as is often the case for self-employed people like myself, I didn't have leave entitlements to fall back on.

I have a wonderfully supportive husband Philip, and three adult children. I am still an avid baker and live on a blissful bushland property in the foothills of the Brisbane Ranges in Victoria with two adored dogs.

Amanda Griffin

Committee Member

My daughter Erin was diagnosed with DIPG in February 2012 at the age of 12. Erin fought brain cancer for two and a half years during which time she became an international advocate for kids with cancer. Erin passed away aged 14 on 1st September 2014.

Throughout Erin's cancer journey, we became involved with numerous organisations in Australia including Cure Brain Cancer Foundation, CCIA, The Cure Starts Now and the Coalition Against Childhood Cancer. Erin successfully brought public and political attention to the lack of childhood cancer and brain cancer research funding within Australia which resulted in the development of the first Childhood Cancer-specific website.

After taking some much-needed time-out to grieve for my daughter, I now feel the time is right for me to become more actively involved in the brain cancer community within Australia. I believe BTAA offers an incredibly valuable resource to brain tumour patients and their families.

Peter Ramstadius

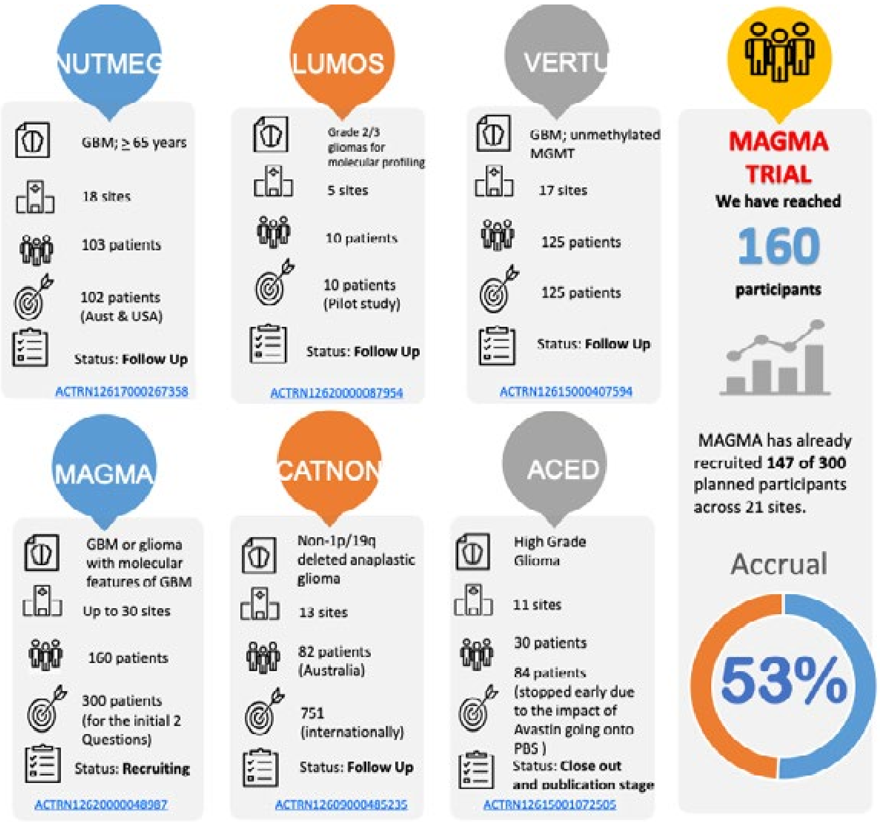
Website Coordinator and Helpline

Peter is a semi-retired civil engineer from Coffs Harbour. He has enjoyed a varied career specialising in construction project management for both government and the private sector, but more recently in a self-employed role working in the mining industry. Peter became involved in the brain tumour community when his wife, Jenelle developed a GBM and passed away in 2017 after a 20-month battle. Jenelle had had an unrelated meningioma removed a few years earlier.

Peter has four adult children and is keen to utilise the knowledge gained through his wife's journey to assist others.

Clinical Trials in Australia Update

A number of brain tumour clinical trials are currently underway. Below is a list of these trials along with the target groups, number of sites and patients, taken from the most recent COGNO newsletter. Further links and information can be found on the BTAA website.



NUTMEG	LUMOS	VERTU
GBM; ≥ 65 years	Grade 2/3 gliomas for molecular profiling	GBM; unmethylated MGMT
18 sites	5 sites	17 sites
103 patients	10 patients	125 patients
102 patients (Aust & USA)	10 patients (Pilot study)	125 patients
Status: **Follow Up**	Status: **Follow Up**	Status: **Follow Up**
ACTRN12617000267358	ACTRN12620000087954	ACTRN12615000407594

MAGMA	CATNON	ACED
GBM or glioma with molecular features of GBM	Non-1p/19q deleted anaplastic glioma	High Grade Glioma
Up to 30 sites	13 sites	11 sites
160 patients	82 patients (Australia)	30 patients
300 patients (for the initial 2 Questions)	751 (internationally)	84 patients (stopped early due to the impact of Avastin going onto PBS)
Status: **Recruiting**	Status: **Follow Up**	Status: **Close out and publication stage**
ACTRN12620000048987	ACTRN12609000485235	ACTRN12615001072505

MAGMA TRIAL
We have reached
160
participants

MAGMA has already recruited **147 of 300** planned participants across 21 sites.

Accrual

53%

Oligodendroglioma Education Day Webinar Video Now avaliable

care2cure
THE BRAIN CANCER GROUP

The Oligodendroglioma Education Day Webinar held on Friday 4 March 2022 was a great success, and is now available to be watched on Youtube at your leisure.

We would like to thank the panellists for providing their valuable time and expertise to inform us and answer crucial questions:

- Radiation Oncologist A/Professor Michael Back
- Neurosurgeon Dr Jonathon Parkinson
- Medical Oncologist Dr Adrian Lee

A big thank you to the webinar facilitator, Marina Kastelan, Neuro-oncology Nurse Practitioner at The Brain Cancer Group and Care2Cure. www.youtube.com/watch?v=IFLYBmKU5rI

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

Rogue Wave Raises Awareness Despite Setback

Rogue Wave skipper, Kevin Le Poidevin, reports on their recent participation in the Sydney to Hobart yacht Race participation to raise awareness of the BTAA and brain tumours. Kevin writes:

Well that race didn't go to the grand master plan!

Our **Rolex Sydney Hobart Yacht Race (RSHYR)** double handed campaign didn't quite go as planned in Dec 2021, so Rogue Wave will be back again in 2022.

Daz and I are community minded blokes who understand and appreciate the commitment of valuable time and knowledge that volunteers unselfishly offer and the support service provided by **Brain Tumour Alliance Australia (BTAA**) and **Soldier On**. Hence we were extremely proud to be supporting our partners to raise community awareness...... and with any luck, a few dollars on the way.

When I suggested to Nathan 'Bullet' Draper I was happy to offer up my 1983 Sigma 36 ft yacht *Rogue Wave* as a promotional platform for a charity/charities of his choosing, Bullet did not hesitate in suggesting **BTAA** and **Soldier On**. Both organisations played key roles in Bullets '**Tumour Trip**' as he calls it.

Next step was to organise the branding to get the message out there. Tristan and Brian Pattinson from Melbourne based sign company **AUSIGN** kindly donated all our hull decals. I had just purchased new **Roly Tasker Sails** from Sam and Greg Newton in Sydney and they put me in touch with Scott Archer from **Imagine Signage** who created the logos. Then it was off to the Soldiers Point Community Hall to spread out the sails and apply the logos.

Logistically it takes months of preparation and significant investment in time and money to get to the start line of the RSHYR (not to mention the return leg). There is boat preparation, safety items to be inspected, training and a qualification passage to be undertaken; and of course crew preparation (physically and mentally) and race strategy planning. As one of the slower boats we know we will always be at the back of the fleet, but hey that's cool with us. Anyone that watches the RSHYR on TV will know they focus on the front and the back of the fleet with little coverage for the vast majority of boats. That's great news for us when seeking exposure for BTAA! In the end we did get some great video coverage from the helicopters and commentary team.

The cannon fires and we are on our way. We started on the western start line with the other 17 double handed competitors. A clean and conservative start was in order given the effort expended just to get here. We had a great run to the heads and turned east heading offshore in a building breeze. We had reduced sail area early knowing it was going to blow hard, so we made good progress. The breeze steadily built all evening and we saw 40 knots in gusts. The sea state was very short and sharp 3-4 metres as the south south-east wind pushed against the southerly flowing current. Waves crashed on deck and over the side relentlessly for about 20-25 hours. Sail area was reduced and then our problems started.

Daz and I ran a 2 hours on 2 hours off roster to ensure we minimised the effects of fatigue. Seasickness lurked in the shadows waiting to strike in these very uncomfortable conditions. This meant only one of us on deck at a time unless doing a manoeuvre such as reefing to reduce sail. Around midnight the autopilot started to disengage at random meaning the course would change placing the boat in a dangerous position. The result could be a knock-down where the mast goes horizontal to the sea or worse crash gybing and losing our mast. The intermittent autopilot gradually degraded requiring hand steering which is extremely fatiguing in these conditions. By midnight on day two just south of Batemans Bay the autopilot failed completely. Our race was over.

After reporting our retirement we headed for Jervis Bay as it was too dangerous to enter Batemans Bay in the dark in gale conditions. We picked up a mooring in Jervis Bay, had a big sleep before unsuccessfully attempting a repair. Even tried putting the autopilot controller in the oven after our Pizza!

We hand steered back to the CYCA and tracked down a spare controller that we installed in 5 mins! Problem fixed.

So as disappointing as it was given the effort expended just to make the start, there are positives as I didn't have to do the return delivery from Hobart!

Thank you to our families, businesses, friends and you the public for all the support and best wishes. We look forward to racing for BTAA again this year.

Regards,

Kev

PROUD SUPPORTER OF SOLDIER ON

Kristin's Story

"You think your nurse is dying?" exclaimed my 19-year-old son, who was at my bedside in the Royal Melbourne Hospital ICU in early 2020.

Surgery had left me unable to communicate with my voice, so I had been trying a different communication method. I would "dictate" messages letter-by-letter; my husband, Tim, would recite the alphabet and I would squeeze his hand when he arrived at the letter I wanted to select. Then Tim would write the letter on a mini-whiteboard.

When my son tried to put together one of these dictated sentences, it seemed I thought my nurse was in peril. Not the case! We all laughed.

And so I (a former newspaper journalist) learned precisely what it was to have a communication disorder.

Ultimately, due to the work with my speech pathologists, this would be overcome.

Rewind a week or so, one summer day in February 2020, an able-bodied me had literally skipped down a couple of stairs leading to a surgical floor of the RMH.

I woke up the next day — after neurosurgery to remove a benign brain tumour (meningioma ay the cerebellaopontine angle) — unable to walk unless two people supported me).

I was also unable to swallow safely, unable to make my voice heard, unable to co-ordinate the movements of my left arm, hand and left leg, and unable to close my left eye. I had left-side facial palsy, I was nauseas a lot of the time, and dizzy all of the time.

This was not the expected outcome of the surgery. What was expected, according to a pre-surgery consult, was: "One week in hospital, maybe a week in a rehab hospital, and eight weeks off work." What transpired was 104 nights in hospital, about three weeks of those in ICU, some of that time on a ventilator; and permanent disablement.

However, I am writing this because since my surgery, I have yearned to hear as many stories of recovery as possible. And this is part of mine, 20 months post-surgery.

In particular, I wish to highlight the stunning work of my speech pathologists.

I wish to explain the transformative impact of the highly skilled application of evidence-based practice using a patient-centred approach.

In the early in-patient days in the rehabilitation hospital, I was fed, watered and medicated via an uncomfortable, albeit necessary, invention: a naso-gastric tube (NGT).

I went for months unable to have a drink of water (let alone coffee!).

My wonderful speech pathologists provided bedside swallowing therapy twice daily.

We practised swallowing firstly on thick fluids, then ice chips and then canned peaches and pears. We also did exercises. After several weeks, and a couple of video X-rays, I was allowed to eat five teaspoons of minced food at mealtimes.

Due to the slow progress of the recovery of my swallow, I had a permanent feeding tube (percutaneous endoscopic gastrostomy, or PEG, tube) surgically inserted into my stomach. I wondered if I would ever eat and drink normally again.

I was discharged with family support, doing 99 "chin tucks" per day, and with my primary source of nutrition and hydration being fortified milk drinks that I poured down my tube.

When my speech pathologist first told me about this swallow-improvement regime, I thought: "Are you serious? Who does 99 repetitions of ANYTHING?"

As an outpatient, I participated in an intensive swallow-retraining program (via telehealth due to COVID) during which I had daily sessions and lots of practice in-between.

My speech pathologists coached me eating, variously, breakfast, lunch and snacks — session after therapy session.

And we rehabilitated my PEG out. Imagine!

I now eat a normal diet and have no medical devices attached to my body. Happy days!

And then there was my voice therapy

In this regard, I feel my in-patient speech pathologists were far-seeing. In hospital I was pretty fixated on retraining my swallow, but my speech pathologists knew it was important to also rehabilitate my voice beyond the level I had reached, which worked well-enough for communication in hospital.

During outpatient voice therapy we rehabilitated my voice from "severe dysphonia" to "mild dysphonia". My voice is now "functional".

All my RMH speech pathology was delivered by professionals who always put the patient first: *How was I feeling? Is now/today an OK time for you to have therapy? Do you prefer peaches or pears?* My therapists gave me as many choices as possible, making me feel as in-control as possible in a health situation over which I had minimal control. They were endlessly encouraging and never gave up believing in my potential.

This experience reminded me of Brené Brown's words in her book, *Rising Strong*: "We don't have to do all of it alone. We were never meant to."

— Kristin Owen, 2021

Gavin McGill's Story

About sixteen years ago, after two weeks of occasional headaches I ended up in hospital. Scans revealed a twenty millimeter mass inside my brain and I had surgery four days later with a full resection. Pathology revealed a Grade 4 GBM (Glioblastoma Multiform)

Despite the bad news I undertook twelve weeks of radio therapy and a further months chemotherapy. It wasn't easy and I had a retinal bleed in right eye during chemo treatment causing a permanent blind spot possibly caused by chemo, so I chose to cancel last infusion just in case. The scans throughout treatment showed stable low intensity residual growth.

There have been minor changes over the years with no medical intervention and minimal side effects. My life goes on with six monthly MRIs and I had a TIA (Transient ischemic attack) twelve months ago that may be attributed to radiotherapy side effects. Luckily I had no other residual side effects.

What else did I do? I had no alcohol, no red meat, no spicy food, no coffee and continued with a healthy balanced diet.

Before I outline the next part of my journey, I want to be clear, I am not advising, recommending, or claiming it was the defining factor of my survival, but it was part of my journey. For 5 years I ground 6 apricot kernels per day, consumed in cereal or juice. Google it and make your own choice.

I made an effort to be active, fit and healthy physically and mentally and embraced Chinese medicine, with a monthly, massage, manipulation, cupping, acupuncture, and herbs as directed.

I also stepped back in my career from national to local responsibilities, reduced stress, and embraced family as my priority. I travelled and enjoyed life as a gift. I watched my kids grow up.

When I turned 50, I raised $17,000 for Cure Brain Cancer fund with family and friends. I supported friends with cancer battles, sharing my experience, listening and caring.

I am still here. I have six monthly MRIs, three monthly visits to a Chinese medical practitioner and I am still embracing life and am fit, healthy and active at 54.

I am sorry I don't have a magic wand to help others, I don't have a miracle cure or treatment, I just count myself lucky. I guess all I have to offer is a story of survival and the ability to give others hope.

Who were my heros:

- Chris Xenos - Surgeon
- Michael Daly - Radiologist
- Ronnie Freilich - Neuro oncologist (my on going specialist since 2003)

—Gavin McGill

“Watch and Wait”

Diane Dunn, BTAA Secretary

I have entered a phase on my brain tumour “journey” called watch and wait. Sounds simple? Not when you dig deeper into both the physicality of repeated scans, and the emotional distress it provokes routinely, like clockwork every three months.

Watch and wait means - lets watch it (the inoperable tumour located in the parietal lobe of my brain) - and observe when it progresses. Note I say ‘when’- not ‘if’. For that is the crux of the watch and wait process. Three monthly MRI’s to check if there have been any changes in the tumour indicative of progression. So every three months I attend the MRI department of my local hospital, have an IV inserted for contrast fluid to be injected - gadolinium (itself somewhat controversial) - and partake in a 30 - 40 minute scan. In my case the results of this scan remain unknown to me for some 5 days until I see my oncologist. So whilst the lead up creates tension “scanxiety”, the physicality of the actual scan relieves some of that - a sense of achievement of having come through the process again. But frustration and tension build again as I wait to find out the result.

The lead up to the scan is a mildly anxious period. The first month immediately after is lived fairly normally - with the next scan seeming such a long time away. By the second month my thoughts begin to turn towards...“it’s NEXT month”. By month 3 I begin counting down the days to scan day - and intrusive and fraught thoughts are hard to contain. The “what if’s” begin - what if it shows progression - what treatment will I be offered, will I require further brain surgery, will I be offered a trial, are there new treatments waiting in the wings for people like me who have completed what is referred to as standard of care. Comical thoughts start too - if I require surgery have I suitable pyjamas, should I make sure I have shaved my legs, should I cut my hair off in advance this time, but more often I am overcome by sadness and fear. Will I only be offered palliative care? What if the brain surgery leaves me disabled and requiring care? How will I cope with the pain and suffering I am putting my family through? Should I consider radical unconventional treatment offered by some at premium cost - and leave my family with additional debt after my still inevitable demise?? For this is the reality of an inoperable and incurable brain tumour - I will not survive it. The question is how long I have remaining. The aim is to live the remaining time as positively as is possible.

Not knowing when you might die is a dilemma of course with which every human being lives. But rest assured, knowing you are living with a life limiting illness for which there is no cure is markedly different to knowing your life will inevitably end - one way or the other at some point in time. Living whilst dying creates huge uncertainty. Uncertainty is very topical in pandemic times - many people not previously aware of the stress of uncertainty have had a small taste of its impacts. Questions posed by those affected by lockdowns and Covid 19 - will I work again, can I afford to spend money, will I remain healthy after contracting it, how will my family cope, will I require hospitalisation, who will look after me, my family, my pets - if something happens to me - are constant companions of those living with a terminal illness. You likely live with hope that Covid19 will pass and life will go back to normal for you. I do not have that luxury. Moreover, I am reminded of it every 3 months. Seasons pass and I wonder if I will see another Spring, Autumn - will I see seasonal cherries again? Should I plant anything that takes years to mature? My future might have included travel in retirement, to see offspring marry/partner/have children or contained vague aspirations to build again, - but undertaking a project which might never see fruition seems careless and foolhardy.

My new normal is called survivorship. It is the period in which you are living after a life changing diagnosis. During this time the values prized by society and held up as markers of a worthwhile life, are taken away or altered irrevocably: productivity; social life; a sense of control; ability to plan. Furthermore, the longer survivorship lasts two strange outcomes accompany your longevity: each stable scan result is met with immediate celebration - then the crushing emotional distress sets in with the realisation that each stable scan gets you closer to the scan which won’t be stable - it’s a simple matter of maths.

Secondly the longer your survivorship lasts you experience the more gradual the falling away of support - people visit less often, overlook your scan / oncology appointments, stop asking meaningful and heartfelt questions about your health and your ability to cope. This is completely understandable but that makes it no less difficult to live with. People “get on with their own lives” - it is a hard slog to support someone for an extended period time - its a marathon not a sprint. Not everyone has a marathon of support in them.

Of course this falling away of support is bolstered by my continuation of “looking good” and stable scans which appear to contradict the existence of the underlying disease.

Invisible illnesses are fraught with these injustices - for brain tumour patients like me, you don’t see the headaches, the noise sensitivity, the fatigue, the confusion with words and meaning, the unsteadiness of gait, the constant state of worry over unusual sensations - the fear of sudden seizures.

See Diane’s full bio on page 9

Toni's Blog Helps Brain Tumour Patients

Blogger, Toni Burness has been writing a comprehensive blog about her brain tumour journey that will be a 'must read' for many brain tumour patients. As a brain tumour patient myself I am always totally impressed by how incredibly skilled, creative and articulate so many of our contributors are, even after considerable trauma to their brains.

Toni writes ; "My hope is to create more awareness about the impact it has on the individuals and their families. If I can help one person then I have achieved my goal."

Below is an extract from the blog and a link to her full story:

Where it all started.......

17 November 2009, I was 19 years old - I still remember the day so clearly. I was in the middle of my 1st year of university exams when I started experiencing severe headaches. I pushed through my first exam the day before thinking that I was just stressed and it was a normal headache. The headache lasted all day and was still there when I went to bed. In the early hours of 17 November 2009 I woke up and could not stop saying "i", "i", "i"... my mum rushed into my room to see what was wrong and then it eventually stopped, I took some Panadol and went back to sleep. Not long after I woke up and my whole body seized up, I was having a full body seizure. My mum, brother and sister all rushed in to help, calling the ambulance and turning me on my side. It was all a blur..... The ambulance rushed me to the hospital. The doctors completed a few tests and were just about to send me home believing it was only stress related, when the speech seizure happened again, I could not stop saying "i", "i", "i". The doctors then sent me off for additional testing including an EEG and MRI. Thinking it was stress related, my family and I did not expect the worst.

The following day we were told that I had a left frontal meningioma which was the size of an apple and could have possibly being growing for the past 2-3 years. Having no symptoms prior to this it came as an incredible shock, I kept thinking this is not happening to me it can't be real....I'm only 19! The doctors recommended surgery to remove the tumour as soon as possible. My operation was scheduled for 5 days later at the Wakefield Hospital in Adelaide, South Australia.

During this time everything was a blur, I wasn't feeling upset or negative about the situation I was in, I was focused on remaining positive. After being informed by the Neurosurgeon about the risks involved with this procedure and signing the paperwork, reality finally set in..... this was life threatening surgery!

The morning of the surgery saying goodbye to my family was the most difficult part; however, I stayed as strong as I could and held back the tears. The surgery took approximately 6-7 hours, I was then placed in ICU. After seeing my family for the first time after the surgery I was so relieved, words can't even explain what I was feeling - I was so grateful that I was alive!

Waking up in ICU the next day I was so determined to get up and go for a walk. Not even 24 hours out of surgery, I was already up and walking around. I was then moved to my own room on the ward. During the first few days I was told to take it easy and just relax, I was allowed to get up for the occasional walk in the hallway with the physio. Four days post op the biopsy results finally came in, I was told that my tumour was a type II Atypical Meningioma, which meant that it has the chance of reoccurrence. The surgeon also informed me that he was unable to remove the whole tumour as it was too close to my superior sagittal sinus (SSS), which is the blood vessel that runs along the top of your brain. They had to cauterize the blood vessel in the hope that it would help mitigate further growth.

I was home within 5 days of surgery and was instructed to take it easy and rest over the next 3 months. My post operative care involved regular MRI's and check ups every 3 months initially, moving to 6 monthly shortly after the first year of follow ups with my neurosurgeon.

Staying positive and concentrating on the support from friends, family and others got me through this time. Unfortunately, this was only the beginning of many hurdles and challenges to come my way.......

A small selection of further chapters:

Our Little Miracle: https://toniburness.wixsite.com/tonimarie/post/our-little-miracle

The Dreaded Infection: https://toniburness.wixsite.com/tonimarie/post/the-dreaded-infection

One step closer to getting a skull: https://toniburness.wixsite.com/tonimarie/post/one-step-closer-to-getting-a-skull

Tissue Expander: https://toniburness.wixsite.com/tonimarie/post/tissue-expander

Or read the whole blog at: https://toniburness.wixsite.com/tonimarie/blog/categories/my-brain-tumour-journey

2022 MHF BEANIE FOR BRAIN CANCER CAMPAIGN

We're very excited about our brand new 2022 campaign and beanie designs!
On May 1st our new campaign and beanie designs will be revealed!!!

You can purchase a beanie from the 1st June 2022 on the Mark Hughes Foundation website or at any Lowes store across Australia and all IGA stores in NSW, Act & QLD.

Our dedicated Beanie for Brain Cancer Week is June 27th-1st July 2022. Get your school, business or organisation involved. You can register a fundraising event at our website markhughesfoundation.com.au

The NRL Beanie for Brain Cancer Campaign is Round 16, June 30 - July 3rd, 2022. Come along to any NRL game during this round and help us raise awareness and funds for research into brain cancer.

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!

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