



THE OFFICIAL BTAA NEWSLETTER

BRAIN CANCER ACTION MONTH EDITION

MAY 2017 EDITION

BTAA.ORG.AU

This newsletter was produced with the assistance of donations.

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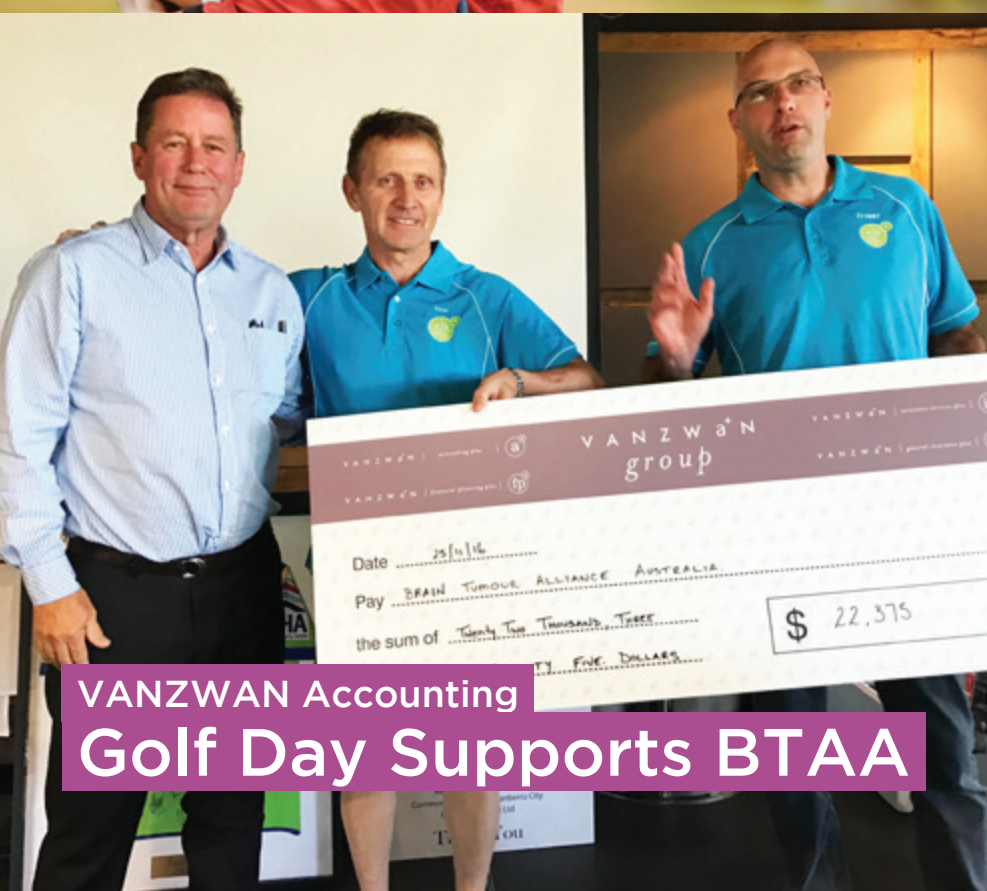
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Brain Tumour
Alliance
Australia



@BrainTumourAA



Search 'BTAA' for
various videos

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



SUPPORT IS AVAILABLE

BTAA Freecall 1800 857 221.
Email btaa@shout.org.au

Peer to peer support around Australia listed on
www.btaa.org.au/page/26/support-organisations

Cancer Connect telephone (13 11 20)

Brain Tumour Patients Telephone Support Group
Freecall 1300 755 632

Monday - Friday 9am - 5pm
or email tsg@nswcc.org.au

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

Centre for Community-Driven Research Support clinic
via telephone. To access this service call 1300 42 68
77 or email nurse@cc-dr.org. www.13004anurse.org

COMING EVENTS

6 May
Cure Brain Cancer Gala Ball, Sydney
www.curebraincancer.org.au/page/231/dining-events-2017

7 May
Footprints for Brain Cancer Walk, Brisbane
www.btaa.org.au/events/18/brisbane-footprints-for-brain-cancer

12 May
Brain Cancer Action Forum
Cancer Council Victoria, Melbourne
Registrations Cancer Council Victoria.
See www.btaa.org.au/events

12 May Metastatic Cancer Alliance Meeting, Melbourne
Convened by BCNA, by invitation.

25 May Brain Cancer Action Forum, Sydney
Registrations for FREE Sydney forum taken on
www.btaa.org.au/events

27 May Mel Goes Grey in May Dinner, Bathurst
www.btaa.org.au/news/100/mel-goes-grey-in-may-2017

27 May Dine for a Cure, Melbourne
www.curebraincancer.org.au/events

2-6 June ASCO Annual Scientific Meeting
Chicago, USA
am.asco.org/patient-advocates

15-16 June
SNO Paediatric Research Conference
New York, USA
www.soc-neuro-onc.org/articles/2017-sno-pediatric-research-conference

17 June Dainere's Rainbow dinner, Canberra
www.daineresrainbow.com.au/gala-dinner-2017

22 July 2017 Red Gala Ball, Ballarat
www.btaa.org.au/news/101/ballarat-red-gala-ball-22-july-2017

DONATIONS

Special Thanks to the following:

- Donations from the funeral of Kay Lyras.
- Donations from the funeral of Bill Hindson.
- Donations from the funeral of Lyn Williams.
- Everyday Hero fundraisers for BTAA.
- Participants for G.M. Allen and McDonald the CBRE Walk for a wish 2016.
- Participants in the Brisbane Trans City 2 Everyday Hero Robertson.
- Participants in the The Sunday Mail Suncorp Bridge to Bridge Everyday Hero Cooper.

Significant individual donations:

- June Leroy
- Michelle Gregory
- Rob McMaster from G.J. Gardner Homes Ballarat
- Peter Rich
- The wonderful the Nicola Scott Educational Trust
- Thanks also to Debbie Pollard, Sylvia Gallagher and Andrew Simpson who contribute regularly.

LETTER FROM THE CHAIR

This newsletter coincides with the May Brain Cancer Action month and we hope you are able to attend some of the events we have detailed in this issue.

This issue also includes details of our Submissions to the Senate Inquiry into Rare Cancers, many thanks to those who contributed and Tricia Berman for coordinating our response.

The 3 year project which we are conducting with funding from Cancer Australia is now in its second year. We are currently seeking Ethics Committee approval for the focus groups that we will be conducting shortly with patients and clinicians to obtain their views on new resources to assist brain tumour patients following diagnosis. A special thank you to Dr Danette Langbecker for assisting in preparing the material for the Ethics Committee.

The International Brain Tumour Alliance magazine will be circulated shortly. It includes an article about BTAA and myself. The article was written at a difficult time shortly after the passing of my husband Bill. We were married for 48 years and I was his carer for the 12 year battle with multiple myeloma. I am grateful to the many BTAA members that have contacted me to express their condolences. I am also thankful for the support of the BTAA committee, and having such a worthwhile cause to turn my energy to.

As Chair, my personal goal is to make sure all newly diagnosed brain tumour patients are provided with support materials. In order to achieve this we need to deliver copies of BTAA brochures and materials to all hospitals, brain tumour nurses and other relevant groups across Australia that are involved with the treatment of brain tumour patients. We are looking for volunteers who would like to be

involved in the distribution of these materials in their local area, so please contact me chair@btaa.org.au if you would like to volunteer.

Another initiative that I am pleased to work on this year is to update our website to make it more user friendly and easier to navigate. Again, if you have ideas on what changes we can make to provide better services through our website, please let me know on chair@btaa.org.au.

Peer-to-peer Support Group

A long term goal of establishing a monthly support group in Sydney was finally realised in October 2016. This would not have been possible without the support of the Chris O'Brien Lifehouse and Dr Brindha Shivalingam, Alice Parsons, Sally Payne and Gerry Tye.

The support group meets from 10-12 on the first Friday of each month at the Chris O'Brien Lifehouse. Reminder emails are sent to our NSW subscribers each month. If you are interested in attending, please contact chair@btaa.org.au, phone 1800 857 221 or visit BTAA.org.au to subscribe to our database.

This meeting is also available via video conference to those in regional areas. Please contact gerry.tye@gmail.com if you wish to arrange a connection.

As our support base grows we aim to establish new support groups in other areas of Australia, and provide assistance and support to already established groups.

Events

We would like to extend our deepest thanks to everyone involved in the Van Zwan Golf Day. The Van Zwan Accounting team has supported BTAA for 4 years, and grows each year. This year they donated an incredible \$22,000 to BTAA.

Thanks to Susan Pitt for compiling a comprehensive list of upcoming brain tumour related events. I'd like to draw particular attention to two fundraising events that will donate a percentage of their fundraising efforts to BTAA.

- "Mel Goes Grey in May" in Bathurst, NSW on 27 May 2017. This event also supports BrainStorm at RPA.
- "Red Gala Ball" in Ballarat, Vic on 22 July 2017 which will also be supporting Carrie Bickmore's Beanies for Brain Cancer initiative.
- "Join Us" in Ipswich QLD on 8 July 2017. This event raises funds for the Nicola Scott Educational Trust, and coincides with the 5th anniversary of Nicola's passing.

If you know of any future events, please let us know by freecall 1800 857 221. We always do our best to support and publicise them to our members.

Educational Grants – for nurses and other allied health professionals and researchers

Educational grants are available to BTAA financial members 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 ANSO internationally.

Thanks to the Nicola Scott Educational Trust for the ongoing educational grant funding. Further details: www.btaa.org.au/news/77/btaa-educational-grants

Peer-to-peer Support Grants

BTAA also provides grants to our financial members who provide peer-to-peer support. Grants are approved on a case by case basis and may be used to attend the BTAA National Summit, held in conjunction with COGNO.

These grants are funded by BTAA's donation revenue. Thank you to our donors.

Contact chair@btaa.org.au for more information.

Catherine Hindson
Chair, BTAA AGM

AGM

At our last AGM in September 2016, a change to the BTAA rules to increase the number of committee members was accepted. We now have an additional 4 committee members, bringing the total to eight. The move allows for greater representation in New South Wales, Queensland and Victoria.

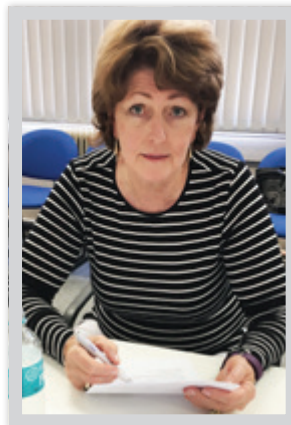
The new committee consists of:

EXECUTIVE MEMBERS

| | |
|----------------------------|-------------------|
| Chair | Catherine Hindson |
| Vice Chair | Philip Steel |
| Treasurer | Patricia Wynn |
| Secretary | Patricia Berman |
| Assistant Secretary | Susan Pitt |

ORDINARY MEMBERS

| | |
|------------|-------------------|
| ACT | Mark Dalliston |
| NSW | Alice Parsons |
| NSW | Sally Payne |
| QLD | Pam Hubner |
| QLD | Julia Robertson |
| VIC | Janet Micallef |
| VIC | Rigoula Roussakis |
| VIC | Mel Tempest |



Catherine Hindson
Chair BTAA Canberra

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.

Brain Cancer Action Week in Melbourne.

By Dianne Legge

Melbourne's community information and awareness forum will be held again at the Cancer Council Victoria on Friday May 12th.

As in previous years, Victorian Neuro-Oncology Care Coordinators together with Cancer Council Victoria and the Victorian Brain Tumour Collaborative Group have put together an interesting program featuring both personal stories and clinical experts in the area of brain cancer and beyond. Program features include an update on clinical trials and research in brain cancer from Cure Brain Cancer Foundations Head of Research, Michelle Stewart, and a number of clinicians working at the coalface. Other sessions will feature information about rehabilitation, work, legal and insurance issues. The final session in the program is focused on communication and support, with Suzanne Shaw from Brainlink.

This BCAW forum is also a great opportunity to connect with other supports and community groups in the area of brain cancer. Each year the forum hosts a marketplace area, where representatives from support organisations and advocacy groups can talk with forum participants about their support services.

The Brain Cancer Action Week Community Information and Awareness Forum is a free event open to all people affected by the diagnosis of brain cancer. The event is on Friday 12th May, 2017 from 10am until 3pm, with registration from 9.30am and is located at the Cancer Council Victoria, 615 St Kilda Road, Melbourne. Lunch and refreshments are provided by ongoing sponsorship from Blackwood 8. Enquiries for the event can be directed to Dianne Legge on (03) 9496 3315.

Register to attend at <http://cancervic.org.au/braintumourforum> by May 9th.

Brain Cancer Action Week – Community Awareness and Information Forum

Living with a diagnosis of a brain tumour presents many challenges - both practically and emotionally. A brain cancer diagnosis can cause fatigue, changes to memory and speech, and presents an array of challenges relating to every-day life including work, finances and body image.

This forum aims to provide information and strategies through presentations and discussions with experts in the brain cancer field. It is free and open to patients, carers, or anyone interested in learning more about brain cancer.

Friday 12 May 2017

Registrations from 9:30am, event starting 10am to 3pm

Location

Cancer Council Victoria, Level 3, 615 St Kilda Road, Melbourne 3004.

Sessions include:

- Directions for clinical trials and research
- Personal stories from patients and carers
- Practical challenges: insurance, rehab, returning to work
- Dealing with the elephant in the room - psychological challenges

For any questions please contact clinicalnetwork@cancervic.org.au

New Lifehouse Support Group Helps Sydney's South

By Alice Parsons

The newly formed Brain Tumour Support Group overseen by Dr. Brindha Shivalingham at the Chris O'Brien Lifehouse, Camperdown, is a wellspring of inspiration and hope; a force against despair. The path for each of us bidden unwillingly into the land of brain tumours is wholly individual. Tumours in all their hideousness are extraordinarily varied. No two stories are alike, and yet we all share a common plight. This is sometimes fear, sometimes loneliness, often frustration and sadly often a sense of being overwhelmed.

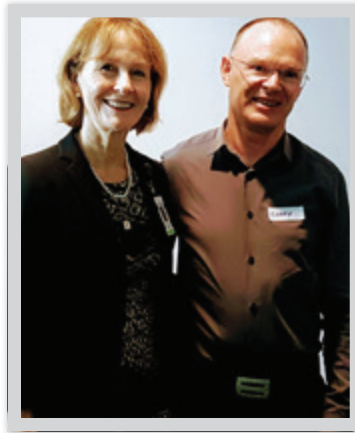
Life for me, as the mother of a brain tumour sufferer, shifted dramatically when almost twenty months ago I telephoned the BTAA hotline. By great good fortune Catherine Hindson answered the phone, and within moments her caring and understanding spirit had enveloped me and renewed my flagging spirits. She filled me with positivity.

The purpose of our support group in Sydney [and what we hope will become a network of support groups all around Australia] is to provide exactly that caring focus and positivity, so that tumour sufferers, carers, family members of sufferers, and so on, might come together regularly in a confidential environment and exchange views, fears, insights, information, experiences; you name it... In less than six months, we have become an extended family which every four weeks extends a little more. Strong respectful friendships are being forged and empathy abounds.

Dr. Shivalingham invites a guest speaker to attend each monthly meeting. This month two experts [both from The Lifehouse] Margery Hellman, a yoga therapy instructor, and Michael Marthick, a physiotherapy specialist, will be speaking. In the past, we have had the pleasure of listening to Gail O'Brien herself, and Dr. Judith Lacey [on the integrative therapies run out of The Lifehouse's Living Room].

Our meetings run for two hours and all comers are welcome. Please be in contact with www.btaa.org.au or email btaa@shout.org.au or call 1800857221 to learn more.

www.btaa.org.au/news/82/btaa-cancer-australia-project



Gail O'Brien and Gerry Tye at the Lifehouse Support group.



Dr Brinda Shivalingham speaking at the Sydney Support Group



The Lifehouse Sydney Support group has been well attended and has fulfilled a need south of the harbour.



Alice Parsons
Committee Member, Sydney

Alice's thirty year old son was recently diagnosed with a brain tumour. Alice is a wife, mother of four, author, editor, troubleshooter, chauffer, custodian of bees and chickens, dog walker and bookworm. Alice hopes that through her participation in the BTAA she can contribute empathy and positivity to those on the brain tumour journey.

Twenty Eight Years of Brain Cancer- Our Story

By Pat and Pete Wynn

28 years ago my husband Pete came home from a long day of driving a Petrol tanker. Our two and a half year old son and one year old daughter were asleep on the lounge.

After walking in through the door and saying some things, that really didn't make a lot of sense, he crouched down, pointed and started spinning around the room. His brother and sister-in-law were visiting at the time and all of us just watched in shock as he crashed into a metal bin, which held wood for the fire, and fell to the floor into what we now know was a grand mal seizure. The seizure lasted for several minutes. He was foaming at the mouth and going blue from lack of oxygen. When he calmed a bit I turned him onto his side and waited for the ambulance to arrive. I thought he'd had a stroke. I had never seen anyone have a seizure so was surprised when the paramedics told me that was what had happened.

After a CT scan and MRI Pete was diagnosed with a brain tumour. It was graded 2-3 mixed Oligiodendroma and about the size of a small orange in the right temporal lobe. He had surgery on 30 August 1988.

Life as we knew it was over. After 2 weeks in hospital, 6 weeks of Radiotherapy and several more weeks of recovery Pete went back to work but not to the driving job that he loved. He was to be retrained in the office. That was ok in theory, however Pete had just had a major operation, his fatigue levels were high, his frustration levels higher as his short term memory was shot.

He was made redundant from that position about 12 months later, to his relief.

Back in those days the driving restrictions weren't as conservative or strict as they are now.

Within a few weeks Pete had another job driving for another company delivering, initially, gas cylinders and then driving gas tankers all over NSW and ACT.

In 1996 Pete had a seizure and was eventually made redundant from that position as well. A series of jobs both driving and mechanical over the next 10 years followed. Eventually he got back into trucks which he was happy with.

In 2004, 16 years later and another son later, a recurrence was discovered on an MRI. We had started to get a bit slack with the annual checkups and we think he had gone at least 2 years between the last clear MRI and the one with a recurrence. We had started to notice a few things that made us get the test done, falling asleep at the wheel being one of them. Falling asleep at the drop of a hat being another. No seizures.

Another resection by the lovely Dr Chandran, a slightly higher grade tumour, of a similar type. It was after this surgery that we were told that this would be how life

was now. He would get more tumours and they would eventually kill him. Up to that point we had no idea that this was a possibility. In hindsight perhaps we just weren't listening. We were seeing enough doctors.

At the time of Pete's initial surgery and treatment there was no treatment other than surgery and radiotherapy. Radiotherapy wasn't an option again but thankfully there was now Temazolamide. Six months of chemo treatment followed and another redundancy as truck driving was his job of choice.

By 2014 when Pete started having funny little episodes, with no sign of anything in between, he had managed to get himself into another job driving trucks. The episodes were focal seizures. Thankfully he was with a major company which worked hard to keep him in a job. The focal seizures turned out to be from residual damage from the radiation therapy. NO tumour this time. However, in addition to the Dilantin he had been taking for the past 26 years he started taking Kepra. This drug turned out to be great at controlling the seizures but increased the fatigue and means Pete lives in a bit of fog.

However 12 months later he started having focal seizures frequently and within 24 hours a small tumour had been discovered on a MRI, despite a clear one 6 months earlier. A recurrence in exactly the same place, although caught very early and measured only 5mm and a lower grade than the 2004 tumour. The dose of Kepra was doubled and so did the side effects.

Another surgery, 5 days in hospital, and the 10 year suspension of the truck driving licence. He was made redundant again in October 2016 from another job he loved. Truck driving is now a thing of the past.

Since the last surgery in August 2015 Pete has only worked 6 weeks, being unable to work quickly enough or stay focused on what he needs to be doing. He gets frustrated and has trouble with motivation. Fatigue is an everyday battle.

Brain tumours are not always a death sentence but they are life changing – for all of us involved in Pete's life.



Pat Wynn
Treasurer, Canberra

Pat joined the BTAA after looking for support for her husband after he had his third brain tumour. She discovered the BTAA website and started attending the Canberra Support group. Pat's experience in book keeping and accountancy helps manage the finances of the BTAA. Pat loves spending time with her grandchildren and hopes to represent the BTAA at conferences to ensure that the BTAA gets the recognition it needs to be able to support those in need.

Strong Submissions To Senate Inquiry

By *Tricia Berman*

On 29 November 2016 the Senate established a select committee to be known as the Select Committee into Funding for Research into Cancers with Low Survival Rates to inquire and report on the impact of health research funding models on the availability of funding for research into cancers with low survival rates. Submissions from interest groups were due on 31 March 2017.

The response has been overwhelming, with over 240 submissions on the Senate submission list as of 17 April 2017. By far the majority (83%) of submissions are by individuals (primarily cancer patients, their families or friends) with the remainder being organisations. In terms of states and territories the breakdown was: ACT 11; NSW 81; Qld 32; SA 8; Tas 9; Vic 41; WA 14; and unknown state/territory (including some national organisations) 44.

If you are interested in reading the submissions to the Senate Inquiry, look up 'senate inquiries' on the web and then select 'Senate Inquiry into cancers with low survival rates' and finally select 'View all submissions' which is an option in the right side bar.

BTAA's submission addressed all the Inquiry Terms of Reference and is listed as submission number 127. Our submission identified the need for a national strategy in Australia to tackle rare cancers with low survival rates. The 14 BTAA recommendations are listed below:

1. BTAA recommends a national 10 year strategy to increase survivorship for rare cancers be developed, with a focus on research, diagnosis, treatment and care services.
2. BTAA recommends that rare cancers research be identified as a separate allocation of funding by the NHMRC.
3. BTAA recommends that the number, type and funding of rare cancer research projects be listed separately by NHMRC and Cancer Australia to inform patients, researchers and clinicians. This will also facilitate brain tumour research to be identified separately from other neurological research.
4. BTAA recommends that Government increase the pool of funding, and access to clinical trials for rare cancer research in Australia by proactively linking our research to leading edge world research.
5. BTAA recommends that the NHMRC makes information on clinical trials (whether clinician or pharmaceutical company led) by stage of trial (open and recruiting) more accessible to brain tumour patients, possibly including having information being made available on Cancer Council websites.
6. BTAA recommends that an Australian Centre of excellent rare cancer research be identified across states and territories to facilitate larger patient numbers for clinical trials and to facilitate engagement with international rare cancer clinical trials.
7. BTAA recommends that federal, state and territory governments assist brain tumour patients and clinicians to participate in brain tumour clinical trials through subsidising travel and accommodation.
8. BTAA recommends funding for the provision of brain cancer care coordinators to assist patients in managing their treatments, including by alerting patients and clinicians to clinical trials.
9. BTAA recommends a national rare cancer campaign across Australia linked to the major players including Cancer Australia, Cure Brain Cancer, the NHMRC and BTAA.
10. BTAA recommends that the National Cancer Registry record malignant and non-malignant brain tumours to assist ongoing research on brain cancer both in Australia and overseas.
11. BTAA recommends amalgamation and transparency of Australian brain tumour information on neurosurgeons and oncologists with a particular interest in CNS tumours so that patients can find relevant treatment centres and hospitals. This could potentially be undertaken by Cancer Australia using Medicare data.
12. BTAA recommends improved patient access to data on Brain Tumours. Remove any obstacles between states and territories to achieving a national brain cancer data set. Cancer Australia is working to improve cancer data sets but brain tumour/cancer data will be delayed with more common cancers with higher survivorship rates getting preference.
13. BTAA recommends specific brain cancer drugs and immunotherapies be fast tracked to the Australian PBS to enable equity of access for all patients desperate to increase their survival time.
14. BTAA recommends improved training and provision of brain cancer care coordination nurses for patients. The positions could be funded through a new National Partnership Agreement with the States and Territories via COAG.

The Senate Committee is to inquire and report by 28 November 2017.



Tricia Berman
Secretary, Public Officer, Coordinator
Cancer Australia Project, Canberra

Tricia is a retired senior public servant and brings a wealth of knowledge and skills to the BTAA. She started volunteering for the BTAA through her connections with other BTAA members. In the times she is not working for the BTAA, she loves to paint and travel, and enjoys entertaining family and friends. Tricia would like to ensure that all brain tumour patients and carers have access to the support and information they need across Australia.

Assessing Fitness to Drive 2016

By Mark Dalliston

Australian medical professionals are required to follow the guidelines produced by Austroads and the ATC (Australian Transport Commission) when assessing brain tumour patients fitness to drive before and after surgery. Recently a new edition came into effect on 1st October 2016. This edition replaced the 2012 version. As well as this all states and territories have specific laws about reporting health conditions that might affect a person's ability to drive safely.

The laws also require drivers to report to the Driver Licensing Authority any permanent or long-term illness that is likely to affect their ability to drive safely. The guidelines go on to say that ; "as the relationship between patient and health professional is a confidential one, the health professional will not normally communicate directly with the Driver Licensing Authority. He or she will provide the patient with advice about their ability to drive safely as well as a letter or report to take to the authority. (Note that in South Australia and the Northern Territory, legislation currently requires the health professional to report directly to the licensing authority if they are concerned about the impact of the patient's health on their ability to drive safely)."

A drivers responsibility is thus to:

To report to the driver licensing authority any long-term or permanent injury or illness that may affect their ability to drive safely.

To respond truthfully to questions from a health professional regarding their health status and the likely impact on their driving ability.

To adhere to prescribed medical treatment.

To comply with requirements of a conditional licence as appropriate, including periodic medical reviews.

It is an oversimplification to say that in general, brain tumour patients are unable to drive for six months after surgery and twelve months after their last seizure as many other factors are taken into account. Patients should discuss this with their doctor and can also read the comprehensive guidelines available in the Assessing Fitness to drive document. (available as a PDF, see below). Patients may also be required to have a driving assessment as part of this process.

I had a craniotomy and I needed to notify my local licensing authority. Some of my symptoms were common to brain tumours, such as seizures; and others less common, such as hemiparesis (weakness down one side of the body). Not reporting can mean penalties of not driving, including fines.

If you lack side-effects after your initial treatment, you are good to drive after six months. The default period for returning to driving is 1 year seizure free. However, there are certain conditions where this reduced to 6 months. For example, after starting initial treatment and within 18 months, going seizure free for six months.

Your first step is getting the required medical approval. My doctor signed off on the form. Once I had my medical form signed, I went to the licensing authority. This was a more difficult stage for me than most because of my seizure and disability.

My licence has restrictions, such as driving an automatic and using a steering nob. Initially, it looked as though I was going to need to drive a modified car with my left foot. I decided to practice for six months to enable me to pass the test with the right foot.

I have had to stop driving twice due to seizures. If I had a seizure now, I am not able to drive for 6 months after my last seizure. I am currently trying to get sign off on my seizures being managed, safe, and obviously not grand mal or focal; or other type, that could interfere with my driving.

A calm head will serve you well. While there is a realistic chance of you driving, I don't recommend you give up. To their credit, the licensing authorities and AustRoads have made progress to make it simpler for those of us who have lost their licence through medical reasons.

www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive



Mark Dalliston
Newsletter editor, committee member, Sydney

Mark finds joy in exercise, peace in the present and love in his family. He is a 6 year survivor of an Oligoastrocytoma. By working with BTAA, Mark hopes that he can make the journey of other survivors easier than it was 6 years ago. Mark has a daughter Cara born shortly after his diagnosis. See Mark's articles in our newsletters. Mark is supported by his wife Susan.

Cancer Australia Grant To Provide Support to Australia's Multicultural Society

By Tricia Berman

During 2016, BTAA was awarded a grant from Cancer Australia to develop new information resources for brain tumour patients and carers. This Cancer Australia BTAA project is looking to translate brain tumour information into at least 5 languages to assist patients from culturally and linguistically diverse communities (e.g. Chinese, Vietnamese, Arabic, and Easy English). This is in recognition of the multicultural nature of Australia's population.

The project Steering Committee and project team met several times in 2016 to look at existing information resources for brain tumour patients, their families and carers. Over 70 resources were found with some 20 being available on the internet.

Steering Committee Members: Dr Danette Langbecker (U Qld), Dianne Legge (Austin Hospital, Melbourne), Sally Payne (IBTA, UTS Sydney) and Dr Jonathan Parkinson (U Syd, NSW)

Project Team Members: Tricia Berman, Janet Micallef, Rigoula Roussakis, Philip Steel, Annabelle Wilson.

In a Forum during the Melbourne Brain Cancer Week (May 2016), attendees were asked to identify what sources of information were useful to them - the Victorian Cancer Council information was the most frequent response.

The Steering Committee held a workshop in August 2016 to identify what type of information resource was most needed - particularly by those who did not have English as their major language. A resource that patients could carry away in their own language from their doctor/surgeon appointment following diagnosis that explained **their type of brain tumour, its location, and their own treatment regime** was identified as useful. Often, patients cannot remember the medical terms used nor are they able to explain to others the type of treatments they are having. Having a graphical picture of the whole brain cancer journey was seen as a very useful take away resource.

Soon, the project is going to hold Focus Groups with patients and carers to see what their thoughts are in regard to some resources proposed for development and translation. It is expected that the Focus Groups will be held in Qld, NSW and Victoria. We will alert you to the Focus Groups in due course.

If you would like more information about the BTAA project please contact secretary@btaa.org.au

Tricia Berman is the Secretary of the BTAA and convenor of this project.



Wagon Nationals Power Support For BTAA

By Lisa Chambers

The Wagon Nationals are in their 4th year running this amazing event. Last year we made the decision as a committee to get onboard with a worthy charity which is close to my heart BTAA.

I have had 2 brain tumours one was removed in May 2014 and I was unlucky that 11 months later I received the news another had grown in my cerebellum. I have lost my mother due to the same brain tumors so doing anything to help BTAA is my goal.

Our event last year was at the Caribbean Gardens on 28th August. We had about 350 Wagons turn up from all over Australia. We also had shareyourdrive come out and do media/filming on the day so we can spread the word about BTAA. We had auctions, raffles and face painting/balloons. The amount of people that turned up to support was overwhelming. We raised \$4500 for BTAA but this year we hope to double that.

This year The Wagon Nationals are back at Caribbean Gardens Sunday 27th August. Bigger and better with Food Vans and Raffles, also our Auction. Please come down to support a great charity.

There is also a GoFundMe account set up to make donations every little bit counts.

www.gofundme.com/donations-for-btaa-wagon-nationals



Turning Lemons into Lemonade

By Stephen Newman

**My brain it got all muddled
invaded by this thing
I had no equilibrium, I had no song to sing
I could live, I thought, or I could die,
or maybe I'd just fade
So I got up and grabbed some lemons
and made some lemonade**

I was diagnosed with a brain tumour in late June of 2016. My wife reacted by saying “our life is going to change.” Without knowing the seriousness of it she knew one thing, that our life would be forever different to the one we had, and would, to an extent, be defined by this invasion of our world. The tumour was compressing my brain stem, and traversing through cranial nerves and three major arteries. I was suffering severe vertigo and I had to stop driving, I had to put a hold on riding my bicycle on the road and the pressure in my head made everything feel heavy, laboured, hard. Day to day decisions were made against the backdrop of getting through.

Just prior to my diagnosis, when out for a what I thought was a routine bike ride, I started to feel as though I might not stay on my bike. I was suffering severe vertigo, not the type of vertigo that makes for an annoying few minutes while you regain your balance but the sort that sends a shiver down your spine. I dismounted and turned the bike around, towards home. I should have immediately hailed a cab but foolishly, I decided to ride home. How I made it, I do not know, without knowing that I had a brain tumour, it had well and truly taken over. I told my wife what had happened, she suggested that riding on the road be off my agenda, that I buy a stationary trainer as a substitute for riding on the road until I sorted out what was wrong.

I had surgery to remove the tumour, a Petroclival Meningioma, three weeks later, a short turn around between diagnosis and action but long enough for me to consider the consequences. I chose not to dwell on them because it would have been self defeating to do so, I chose instead to trust fully my neurosurgeon and the medical care we have in this country. I awoke the morning following surgery, in the ICU ward, after a 15 hour operation, barely cognisant of anything. I had no movement down the left side of my body, I couldn't even wiggle my toes. My right eye had been forced shut from the trauma of surgery and I had an eight inch long scar down the side and along the top of my head.

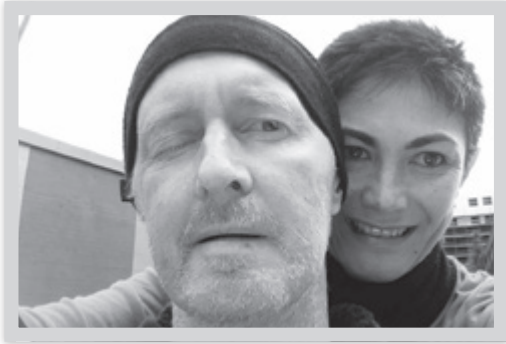
I spent a total of eight weeks in hospital, where I learnt to walk again, to string a sentence together, and to get to a point where I could see light at the end of the tunnel.

I had lost 12 kilograms in weight in a very short period, most of it muscle mass. I put that down, primarily, to being fed through a tube for a couple of weeks following surgery. My legs were like matchsticks, I couldn't put any force through my left leg, let alone ride a bike. My entire left side was numb, useless to the point of complete immobility.

Three weeks at North Shore was followed by a further five weeks in a rehabilitation facility. I was described, by more than one specialist, as “damaged and disabled”. I dealt with that confronting description by pushing harder the physiotherapists to get me back to walking. I decided that I couldn't afford to accept as reality that terminology, even though, at that point, I couldn't walk, confined to a wheelchair and being showered by my wife and my nurses. My left arm was lifeless, hanging flaccidly by my side, good for nothing, mournful in its countenance. Doctors and nurses would direct questions to my wife rather to me because they knew I couldn't answer, it frustrated me, it made me angry, not at them but at the situation as it was. She would leave the room when friends came to visit because, apart from taking the opportunity to get some respite, she wanted both my friends and me to have the visit stand on its own merits, for me to work, to find a way to communicate what was going on in my world without her doing everything for me.

My speech, when it came, was laboured, I was sapped of energy in trying to express myself, and I found the words of encouragement from others patronising when of course they were anything but. It was hard. I told myself that being called damaged and disabled, words that can come so easily, from experts and lay people alike, were merely part of the recovery process, tests of character along the way. I saw myself as a fighter, even though there were days when I wanted to mentally “check out”.

My wife took many photos and much video footage of my trying to walk, the early stages, the progress, the victories, if only to capture a record of my actually moving, a glimmer of hope amidst the confusion. I still watch some of that early footage, it provides me encouragement, it tells me how far I've come. It makes me realise that even though there are discouraging moments, periods and days, never giving in to the voices that want to make you “check out” can make the effort to not give in worthwhile. I was encouraged beyond words by the visits of friends, my brothers, reconnecting with them, other patients who were fighting their own battles, by their mere presence, by their odd few words of encouragement, by the look in their eyes and by the way they never let themselves be betrayed by what was on the surface.



My wife's mantra became "Whatever it Takes" whereas my overwhelming response was "Leave me Alone". I had to filter out her obvious desire to get me to the next stage of my recovery and temper it with my own inner voice that cried out for some peace and quiet from the noises and information coming at me and the understandable imploring of those who love me. I had to find a way to motivate myself and dig in. It took some time but it eventually came, as a result of small steps being made and from an overwhelming desire to go home. The irony, of saying, each and every day, from a week after surgery onwards, "that I'm ready to go home now" did not escape me. It took some time for me to realise that whilst I am the master of my own destiny, there are others who have not only my best interests at heart but also the knowledge and expertise to enable me to get there.



By the time I left rehab I was able to ride the stationary gym bike for 10 minutes. I told my wife that my goal was to be back on my bike, on the road, by the end of the year, a goal I now know, to be wildly optimistic. I was still 68 kgs, as opposed to my normal 80 kgs but I felt at least I would be able to make use of my bike when I got home.

Upon returning home from hospital, I made my first tentative foray on my bike. I managed a gentle fifteen minutes. It was, at that point, all my legs would allow. For the first two weeks, fifteen minutes on the trainer became a badge of honour, at least I was able to ride. My preferred riding destination became a loop around a virtual London, or in my case, in those early stages, a stretch of road in London. In the subsequent months since surgery I have graduated to three or four times weekly rides of forty minutes, sometimes over an hour, my longest ride being ninety minutes a couple of weeks ago. Being on the bike provides a balance and stability that I don't have whilst walking, it liberates my spirit and helps to make me feel normal again.



My course of radiotherapy, originally set for six weeks of daily treatment, was reduced to a single treatment, when my oncologist rang me with the good news that my radiotherapy could be delivered in a single hit, as the remaining small amount of tumour was not impinging my optic nerves. There are always snippets of good news to hang onto, to celebrate. My double vision, although still, for the moment with me, is now alleviated by prescription glasses, my left arm is still not working at full strength, it gets regular pins and needles and numbness and my balance has still not returned. This is my new current reality but I revel in learning new things about myself, about how to adapt to my new life.

I still have a long road to recovery but it's not all uphill. I've been through the worst of it. I have been fortunate, to not only have an outstanding surgeon and support team but to have been able to get on my bike and realise that not all dreams have to be jettisoned. All of these things have helped me stay motivated.

In a comical ironic twist, I feel as though surgery to remove my brain tumour has made me a better person. Rather than become angry and despondent, I have become grateful for the things right in front of me. They're gifts. I smile and I laugh more often. I celebrate little things, pausing and giving thanks that, even though many things are harder, I can do them at all. We've managed to turn lemons into lemonade. Our lives have indeed changed but whilst the past year has been undeniably hard, it has also been unquestionably good.

Mel Goes Grey Again

By *Tricia Berman, BTAA Grant Coordinator*

Bathurst fund raising dynamo, Mel Johnson, is once again hosting one of her fabulous dinners to raise money for brain tumour support and research. This year's event will be on May 27, 2017 at Rydges, Mt Panorama in Bathurst.

Mel's enthusiasm for the brain tumour cause is always catching, as the large turn out at last year's event shows. The Bathurst community can also be rightly proud of their spirit of support for the event, both through their attendance and by providing so many great prizes for the various silent auctions, raffles and competitions that are run throughout the night.

Mel recently attended the Sydney Support Group at the Chris O'Brien Lifehouse to present a cheque to Dr Michael Buckland and Dr Kimberley Kaufman for research at Brainstorm RPA.

Many will also be travelling from across the country to support this great event and an important date in the brain tumour community calendar.

For tickers contact Mel on 0401 138 323. See right for more information.

MEL'S 'GO GREY IN MAY' DINNER



Fundraising Dinner for Brain Cancer Research

- Come and join us for a fun night out and a beautiful 2 Course dinner at Rydges Mt Panorama
- Live music and talks given on the latest in Brain Cancer research
- Get your friends together and make a table of 8
- Only \$70 a head with all proceeds going to the Brain Tumour Alliance Australia and Brainstorm at Royal Prince Alfred Hospital

For tickets contact Mel on 0401138323

May 27, 2017 6pm
Rydges Mt Panorama



Peter Vanzwan and David Boucher of VANZWAN Accounting Plus present the cheque to BTAA representative Philip Steel

Special thanks to the following generous sponsors:

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Sydney Swans

VANZWAN Accounting Golf Day Supports BTAA

VANZWAN Accounting Plus has once again held its annual golf day in support of the Brain Tumour Alliance Australia. This community minded Canberra based accounting firm combines its annual golf day for team members and clients with a luncheon, raffle and charity auction.

This year the day raised \$22,375, a truly phenomenal result, and a testament to the hard work of Peter Vanzwan and David Boucher and the whole Vanzwan team in running the event. The generosity of the sponsors and the participants in the various raffles, auctions and competitions held on the golf day is just outstanding.

The work of the VANZWAN Accounting Plus group will go a long way to help us meet our aims to SUPPORT, INFORM, REPRESENT and CONNECT patients, families and carers in Australia's Brain Tumour community. Thanks VANZWAN.

Kick Brain Cancer Art Auction



Nathan Stones, Director of Kick Brain Cancer, Dianne Bradshaw, Co-director of Kick Brain Cancer, and Joshua Chalmers, Ambassador of Kick Brain Cancer, or Nath, Di and Josh.

Kick Brain Cancer started initially as Turtles for Tumours late in 2015, when my husband Michael was undergoing chemo and radiotherapy for an anaplastic astrocytoma. Michael was a big part of the comic and geek community in Melbourne, he was comic artist, graphic artist, member of a popular podcast (Whatcha) and also a host of 32 Geek Street that was on Channel 31. So he was well known and loved within the community.



Then as Michael got progressively unwell his friend Nath wanted to think of another way to raise money for brain cancer. He put the word out to all their artistic friends and asked for donations of artwork that could be auctioned off with all money raised going to Cure Brain Cancer, and that's how Turtles for Tumours was born. We chose Cure Brain Cancer because we understood the almost insignificant amount of government funding that was attributed to brain cancer. Michael was a huge fan of the Teenage Mutant Ninja Turtles so the theme of TMNT seemed fitting and that's how we got our initial name.

Following Michael's passing in March 2016, Nath and I made the decision to keep the organisation going and to change our name to Kick Brain Cancer. was to make our mission very clear. KBC was actually a hashtag that we had been using since our first auction so it seemed fitting.

We are only young so we have only had our first auction and a trivia night so far, as our major fundraisers which we plan on being annual events. We have raised over \$20k so far, but we have big hopes.

Our ambassador is Josh Chalmers! Josh is a great fit for us. As you know he is fiercely positive, very funny and most importantly for us, a huge fan of all things geek. Josh's first job as our ambassador was to choose the theme for this year's art auction which is Star Wars.

Submissions are still open for this year's auction but so far we have around 40 pieces of artwork with more on their way. The quality of art this year has been amazing so we have our fingers crossed that they'll make a lot of money when they go to auction.

We will be holding the exhibition from May the 4th (Star Wars Day) until May 7th in the gallery. All artwork will be exhibited. We have artists donate from all over the world which is great! The auction will be online so everyone has an opportunity to pick up a great original piece. All money raised goes directly to 'Cure Brain Cancer'.

See the coolart at ArtBoy Gallery @ 99 Greville St, Prahran VIC 3181.

From May the 4th to May the 7th - Star Wars Theme.

Opening night 6pm gold coin donation entry.

Hunter Brain Cancer Forum Success

By Sandy Nixon & John Hunter Hospital



Brain Cancer Care Coordinator, Sandy Nixon and Medical Oncologist, Dr James Lynam at the Hunter Brain Cancer Forum



Mark Hughes and his foundation have been a great support to Hunter brain tumour patients.

The first Hunter Brain Cancer Forum, which was proudly sponsored by the Mark Hughes Foundation (MHF) was held on the 3rd March 2017 at Wests Lambton, Newcastle.

The MHF is a not for profit organisation formed in Newcastle by Mark and Kirralee Hughes following Marks diagnosis with Brain Cancer in 2013. Mark is a well known and highly respected former Newcastle Knights Rugby League player, business and community identity who has undergone treatment to fight brain cancer and is currently closely followed-up by his medical team. The MHF has been formed to raise much needed funds to promote research, heighten awareness and support brain cancer patients (children and adults) and their families within the community.

The role of the Brain Cancer Care Coordinator started just over a year ago and is entirely funded by the MHF. Since the commencement of the role we have recognised that there is a lack of information, resources and support available for patients, carers and families diagnosed with primary brain cancer who are going through the most difficult time of their lives. We also unfortunately quickly recognised that we have enough patients within our local health service to be able to hold our own patient and carer Forum.

There was an incredible turnout of over 80 attendees including patients, carers and family members. We were lucky enough to have excellent guest speakers present including medical oncologist Dr James Lynam, radiation oncologist Dr Mahesh Kumar, neurosurgeon Dr John Christie, clinical psychologist Benjamin Britton and social worker Laraine Cross. After each session of guest speakers, we had a panel discussion in which the audience asked further questions. This time was vital as it allowed patients, carers and families to ask questions they may not usually get the opportunity to do so with their medical team.

As many patients understandably were unable to attend, we videoed all presentations which can be found on the MHF website (www.markhughesfoundation.com.au). We were also extremely grateful to BTAA, CanTeen and the Cancer Council for volunteering to hold a stall each on the day to provide attendees with further essential information and resources.

The day was an absolute success, many patients and carers stating that one of the most helpful parts of the day was having the opportunity to meet others going through the same challenging journey as themselves. From the overwhelming positive feedback we received about the day, there is no doubt the Hunter Brain Cancer Forum will continue as an annual event.

A number of other Mark Hughes Foundation events are also on the way this year. They include:

- The hugely popular Beanie for Brain Cancer Awareness campaign is scheduled for 19 - 23 June 2017 and we need your help! Grab your school mates or work colleagues and join us to tackle brain cancer. More details and brand new 2017 MHF beanies coming soon so watch this space on the MHF website or Facebook page.
- Enjoy a quality night of live entertainment, dancing, food and auctions at the 3rd annual MHF Magic Ball. We are excited to announce this popular event will be held on 19th August 2017 at the Newcastle Auditorium, Newcastle Exhibition and Convention Centre from 6:30pm. Tickets on sale from 12pm Monday 29th May via our website.

If you would like to donate to the MHF, donations can be made via the MHF website: www.markhughesfoundation.com.au.

Plan Sets Agenda for BTAA Future

By Philip Steel

The committee members of the BTAA have spent quite a bit of time thinking through the future role and direction of the BTAA during 2016. Some of the questions that have been considered includes:

- **What is our purpose?**
- **What do we want the BTAA to be like in the future?**
- **What do we do well?**
- **What do we need to improve?**
- **What new programs are needed?**
- **What are our key operating principles?**
- **How we ensure the sustainability of the organisation?**

After some considerable thought and consultation we have decided on the following mission statement:

The BTAA supports, informs, represents and connects patients and carers affected by brain tumours.

Support we support the needs of Australians affected by brain tumours through our services, resources and programs

Inform we develop and provide high quality information in a range of formats including information that can empower participation in decisions about treatment and care.

Represent we advocate on behalf of Australians affected or at risk of brain tumours to ensure their voices are heard, and for improved care and research

Connect we connect people and organisations in the brain tumour community

Our vision statement for the future will be:

“Australians affected by brain tumours receive world class support, information, treatment and care.”

Supported by these values.

We

- Understand and care
- Support patients, families and carers
- Base our information on the latest research
- Are a free service

Some of our planned future directions include:

Support

- Continue and strengthen the current 1800 and information pack service.
- Seek to ensure access to support groups throughout Australia.
- Provide training for telephone counselors and support group leaders.
- Develop Paediatric support programs including the use of new technology.

Inform

- Continue to develop the newsletter, website and social media for information sharing.
- Promote brain tumour awareness and education throughout Australia.
- Develop more Australia specific brain tumour materials.
- Provide regular updates on new and emerging treatment and care options.
- Develop materials for other language and disability groups.

Represent

- Provide a regular forum for members of the brain tumour community to raise issues and voice concerns.
- Ensure that brain tumour and patient issues are represented at all times in all levels of government.
- Ensure that Australians have access to the best treatment and care information from throughout the world.

Connect

- Ensure that we have representative and participants from all parts of Australia involved in the BTAA.
- Develop our current conference and meeting program.
- Ensure that all groups in the brain tumour community connect regularly to provide one national voice.
- Continue our connection and support of health professionals.

This is a very full agenda for what has been up until now a wholly volunteer organization running on a very modest budget, but we are confident that with the support of many we can achieve these goals in the future.



Philip Steel - Vice Chair, Co-convenor of the ACT Brain Tumour Support Group

Philip is a retired high school Principal diagnosed with a meningioma in 2011. Philip is married with three children and is a keen gardener, sometimes artist, mechanic, home renovator, cyclist, surfer and paddler. Philip is co-editor of the newsletter and is working to develop BTAA's new strategic plan, as well as being the convenor of the ACT support group.

Brain Cancer Action in Melbourne

Friday 12 May 2017

Registrations for the Melbourne forum are open on the Cancer Council Victoria site.

The Melbourne Brain Cancer Action Week Community Information and Awareness Forum is a free event open to all people affected by the diagnosis of brain cancer.

The event is on Friday 12th May, 2017 from 10am until 3pm, with registration from 9.30am and is located at the Cancer Council Victoria, 615 St Kilda Road, Melbourne.

Lunch and refreshments are provided by ongoing sponsorship from Blackwood 8.

**Enquiries for the event can be directed to
Dianne Legge on (03) 9496 3315**

Brain Cancer Action in Sydney

Thursday, 25 May 2017

The Sydney NSWOG Patient forum - Wesley Conference Centre City.

The forums are suitable for carers, patients and family members of persons living with a diagnosis of a brain tumour. Allied health professionals and researchers are also welcome.

Venue: Wesley Conference Centre, 220 Pitt Street, Sydney, on Thursday 25 May - Registrations from 10 am, opening at 10:30am until 3:15 pm. Lunch provided.

**For more information on accommodation assistance
email Kaye: kduffy42@gmail.com
Registrations for the Sydney forum is now available
on the BTAA website: btaa.org.au**



SPREAD THE WORD!

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



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Search 'BTAA' for
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