



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

THE OFFICIAL BTAA MAGAZINE

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK EDITION

OCTOBER 2019 EDITION

BTAA.ORG.AU

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PHARMACY STUDENTS SUPPORT BRAIN TUMOUR PATIENTS



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

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

BTAA Committee 2019 - 2020

Executive Members

Chair: Catherine Hindson

Vice chairperson: Janet Micallef

Secretary: Michael Bradley

Assistant Secretary:
Billy Williams

Treasurer: Pat Wynn

Ordinary Committee Members

Janet Micallef, Michael Parsons,
Pam Hubner, Alice Parsons,
Diane Dunn, Amanda Griffin,
Di Pooley, Eliza Moloney

Specialist Advisers:
Denis Strangman AM,
Matthew Pitt and Susan Pitt

Magazine/e-news Editor:
Philip Steel

Public Officer:

Eliza Moloney

Website Coordinator :

Peter Ramstadius

WA State Coordinator:

Diana Andrew

We are always looking for more helpers and representatives, especially in regional areas and states that currently do not have representation.

LETTER FROM THE CHAIR

Letter from the Chair.

2019 has been a very busy year for BTAA and its committee members. We have made some major steps forward to improve patient and carer support that will mean improved services into the future. The new website will make support and information much easier to access as well as streamlining the administration of the organisation. The new ten language, multilingual resources including the "Pathway" document and the "It's Okay to Ask" booklet, will provide a much needed resource for all Australians into the future. The new monthly e-news will provide all members of the brain tumour community with timely information about news, events and research progress. While BTAA remains a volunteer organisation, we now have a small amount of administrative assistance to ensure that all requests for help and support are managed promptly. This increased level of activity has led to an increased burden on the hardworking Committee Members, and we will need to look for more helpers to manage specific areas in the future if we are to continue to grow and flourish into the future.

The **Cooperative Trials Group for Neuro Oncology** will hold their 12th **COGNO Annual Scientific Meeting** from Sunday 27th October to Tuesday 29 October 2019 at the International Convention Centre Sydney NSW.

On Sunday there will be a patient forum. To register for the forum go to the event page on the BTAA website.

The COGNO conference coincides with the 13th **International Brain Tumour Awareness Week**, from Saturday 26th October to Saturday, 2nd November 2019.

During May, **Brain Cancer Action Month**, we launched brain tumour resources that BTAA and the project team had developed, in Sydney, Canberra, Hobart, Adelaide, Melbourne and Brisbane, - "A **Pathway** document" for patient information and a booklet of questions, "**It's Okay To Ask**". The English **Pathway** document has been distributed as a desktop pad to Surgeons and Oncologists. The printing was largely donated by **Barter Card Canberra**. The 10 translated languages can be downloaded from the BTAA website. (Arabic, Chinese-simplified and traditional, Dari, Pilipino, Greek, Hindi, Italian, Vietnamese, Punjabi and Spanish.

It's wonderful that this three-year project, partially funded by Cancer Australia, to develop brain tumour resources for the Culturally and Linguistically Diverse (CALD) Communities is completed.

I would like to thank the Tricia Berman (BTAA Secretary), who lead the project and the project team Dr Jonathon Parkinson (Neuro Surgeon), Dr Danette Langbecker (Research Fellow), Dianne Legge (Brain Tumour Support Coordinator), Sally Payne (IBTA Senior Adviser), and committee members Janet Micallef, Susan Pitt, Philip Steel and the late Rigoula Roussakis.

Also during May Brain Tumour patients forums were held in Sydney, Hobart, Adelaide, Brisbane. BTAA intends to hold these forums again next May. The Cancer Council in Hobart and Queensland made this desire a reality.

In February BTAA commissioned OPC to develop a new website. It was launched in May to coincide with the launching of the CALD project. This project was initially led by Stephen Newman who prepared the Project Plan and organised the search for a suitable web developer, and Peter Ramstadius who was the project manager and interface between the committee and OPC to ensure a fully functioning website. I am extremely proud of our new look website.

Fundraising

This year we have been extremely fortunate to have two organisations raise necessary funds for BTAA.

Firstly, **The One Light Charity Foundation**, which is the Charity arm of **Bartercard Australia business network** ran a National Fundraising Campaign during May, Brain Cancer Action Month.

Colin McCulloch (brain tumour warrior) from Canberra's Bartercard was the face of the campaign and it was his wish to include and unite all ACT brain tumour charities. A total of \$77,000 was raised and shared between Cure Brain Cancer, Dainere's Rainbow Brain Tumour Research Fund, Brain Tumour Alliance Australia, and Colin. The donated funds from Bartercard members can be used by BTAA to do printing, and produce and print teeshirts for fundraising will make a huge difference.

The second group to choose Brain Tumour Alliance Australia was the National Association of Pharmacy Students (NAPSA). Each year during April and May NAPSA have a Charity Cup where they raise money at all the universities and give the funds to a chosen charity. Last year a beautiful pharmacy student from Adelaide, Alycia Easton was diagnosed with a GBM and she suggested us. Sadly before the end of the campaign Alycia died. We are so grateful to Alycia and the NAPSA team for the \$30,177.79 raised, which is the largest donation we have ever received. Its wonderful 2,500 plus students now know about the BTAA and can advise their clients into the future.

We are also extremely grateful for the individual donations made over the last twelve months, unfortunately they were \$20,000 less than the previous year.

Finally I would like to thank all the committee, especially Philip Steel, our Vice-Chair for assisting me and producing the magazine and taking over the e-news, and our Treasurer for keeping our books perfect for the auditors.



Catherine Hindson
Chair BTAA Canberra

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

BTAA Activities for 2019

As always, BTAA focusses on providing support to brain tumour patients, carers and their families. We do not raise money for research but work cooperatively with the many wonderful organisations that do. Our main areas of operation are:

- **SUPPORT** – supporting all brain tumour patients and carers and their families
- **INFORM** – communicating the messages of BTAA to patients and carers and ensuring that patients, carers, their families and medical professionals have access to the latest information
- **CONNECT** – connecting patients, carers, families and brain tumour organisations across Australia and in the international community
- **REPRESENT** – advocating for patients, and representing the BTAA community

This has been a very, busy year for the BTAA. Here are some of the activities that have occurred:

SUPPORT

- Provision of a 1800 Freecall number for brain tumour patients and caregivers to call and receive peer-to-peer advice and support. The team is coordinated by Billy Williams and includes Janet Micallef and Catherine Hindson. There were 174 calls to the 1800 847 221 number in the past 12 months, with May being the busiest month with 44 calls.
- In 2018/19, BTAA posted 201 packages of support materials to patients, their families and carers. Patients can request these resources at no cost through the BTAA website.
- The brain tumour information developed for the Culturally and Linguistically Diverse (CALD) Communities that BTAA and the project team developed, was launched during May, Brain Cancer Action Month, in most states. Launches were held in Sydney, Canberra, Hobart, Adelaide,

Melbourne and Brisbane, of the “Patient Information Pathway” document for patient information, and a booklet of questions for your clinicians, “Its Okay to Ask”. The pathway document has been distributed as a desktop pad and was printed free by Barter Card Canberra. The English version is available in hard copy from BTAA and has been distributed widely to doctors. The 10 translated languages can be downloaded from the BTAA website. (Arabic, Chinese-simplified and traditional, Dari, Pilipino, Greek, Hindi, Italian, Vietnamese, Punjabi and Spanish.

INFORM

- In February BTAA commissioned OPC to develop a new website. It was launched in May to coincide with the launching of the CALD project and should provide users with a new and enhanced experience.
- BTAA Magazines were mailed out to 1,500 subscribers in September 2018 to mark International Brain Tumour Awareness Week 2018, and in May 2019 to mark Brain Cancer Action Week 2019.
- e-News has been emailed to more than 2,100 subscribers since May 2018 and BTAA is now producing a monthly e-News. Since July the e-news has now moved into production through our SHOUT (Self Help Organisations United Together) offices.
- Our Facebook Page continues to be very popular, and in conjunction with the Brain Tumour Support Group Australia Facebook page provides a lively and informative place for news and discussion.

CONNECT

- BTAA attended 23rd Annual Meeting and Educational day of the Society for Neuro-Oncology (SNO) in New Orleans.
- As occurs each year, BTAA attended the annual COGNO conference held this year in Brisbane in October 2018,

and hosted one of the keynote speakers in conjunction with the Mark Hughes Foundation. BTAA also held, in conjunction with the Queensland Cancer Council, a Patient Forum the day before the conference, which was well attended and included some of the international speakers from COGNO.

- BTAA continued its involvement with the NSW Oncology Group, with participation in meetings every 2-3 months.
- In Brain Cancer Action Month – May 2019– BTAA assisted patients to register and attend forums. The NSW Neuro-Oncology Group (NSWOG) hosted the Brain Cancer Action Month Patient Forum in Sydney. BTAA also attended the Mark Hughes Foundation patient forum in Newcastle held in May 2018. BTAA held patient forums in Canberra, Hobart, Adelaide and Brisbane at the Cancer Council in that state.

REPRESENT

- BTAA agreed to assist with coordinating patient educational session at the North Shore Hospital in 2020.
- BTAA assists the formation and conduct of monthly brain tumour support groups including the ACT and Sydney groups.

Thanks to Alice Parsons, Stephen Newman, Gerry Tye, Virginia Ryan, Di Pooley, Michaela Tuppel, Pat Wyn, Billy Williams and Denis Strangman.

REMINDER

Brain Cancer Patient Education Forum

27 October 2019

Darling Harbour Sydney

See details in this newsletter.



'Pharmacy Students Australia Support Brain Tumour Patients

Pharmacy students across Australia have made BTAA the focus for their fundraising in 2019. The National Association of Pharmacy Students Australia (NAPSA) held events associated with most university campuses that have Pharmacy Faculties during May and raised more than \$30,000 for Brain Tumour Alliance Australia.

Unfortunately, the South Australian event had to be postponed after the tragic death of Alycia Easton, a fellow pharmacy student, who passed away after suffering from a Glioblastoma Multiforme (GBM) just a few days before the event. Despite the setback the SA team were able to regroup and hold their event a month later in honour of Alycia.

BTAA Chair, Catherine Hindson praised the efforts of the NAPSA students who worked so hard to raise money. "It was wonderful to see so many young, bright and fun loving students work so hard and give so generously to support the work of the BTAA. The money will be used to ensure that our 24/7 telephone support line, information packs and our patient support meetings reach more people across Australia into the future," she said.

All of the BTAA team would like to pass on their heartfelt thanks to all of the students at NAPSA who contributed to the fundraising events.



SA Pharmacy Students Raise Funds for BTAA

Amanda Griffin

The Cocktail Evening organised by the South Australia Student Pharmaceutical Association (SAPSA) Cocktail was held on 16 August. The fund-raising event was held in Adelaide's Cathedral Hotel in honour of 22 year old Alycia Eaton, who sadly passed away in May this year from Glioblastoma Multiforme. Alycia was a dedicated SAPSA (South Australian Pharmacy Students' Association) and NAPSA member.

SAPSA held both a quiz night raising \$2,623.38 and the cocktail evening which raised an additional \$2,301.50, bringing the overall fundraising efforts by SAPSA to a grand total of \$4,924.88 for Brain Tumour Alliance Australia. The local businesses that made donations for these events were Jack Estate Winery, Warrnambool Cheese and Butter Factory and Dickins Delights for donating chocolate toffees.

It was a pleasure to have the opportunity to speak at the event and share information about the amazing support services offered to brain tumour patients, their families and carers by the Brain Tumour Alliance Australia.

Thanks to Luke Laube, social secretary of SAPSA, who kindly welcomed me at the event and was involved in the organisation of both fundraising events, alongside other SAPSA members, including Jess (Han-Fang) Hsiao, a dear friend of Alycia.

Earlier this year in May, NAPSA members raised a total of \$25,277.79 which is the largest donation ever received by BTAA. With the additional \$4,924.88 raised by SAPSA, the total fundraising efforts by NAPSA combined is a phenomenal \$30,202.67.



Multilingual Resource Launch Across Australia

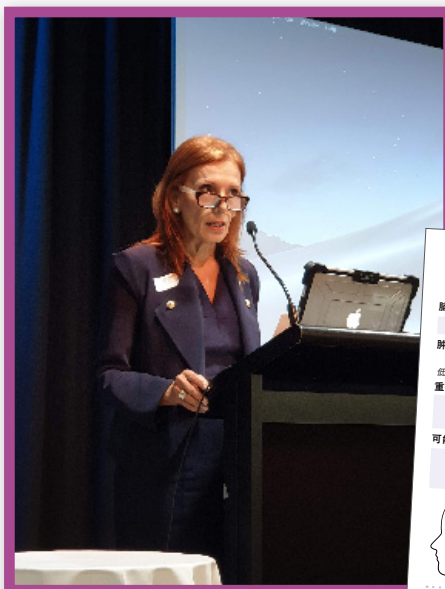
The BTAA's new multilingual resources were launched at events held across Australia during May.

Resource launch events were held in Sydney, Canberra, Melbourne, Hobart, Adelaide, Perth, Newcastle and Brisbane. The launch events were a chance to introduce doctors to the new 'Pathway' document and 'It's Okay to Ask' booklet, and to distribute copies of these resources to the medical profession for use on a day-to-day basis. The resources are available in English as well as ten other common languages in use in Australia. Attendees at the event were also able to preview our new website including the subtitled videos now available. The 10 translated languages can be downloaded from the BTAA website. (Arabic, Chinese-simplified and traditional, Dari, Pilipino, Greek, Hindi, Italian, Vietnamese, Punjabi and Spanish).

Patient forums were also held on the following days in each of the cities above, except Perth. The events were attended by patients, patient advocates, medical professionals and prominent doctors and had a full programme of lectures from some of Australia's leading experts in neurosurgery, neuro-oncology and radio-oncology.



Sydney Launch attendees



Head of Cancer Australia
Dr Helen Zorbas at Sydney launch



Dr Pranavan (Oncologist The Canberra Hospital), Meegan Fitzharris (ACT Minister for Health), Trish Berman (BTAA Secretary) and Catherine Hindson (BTAA Chair)





Doctors and BTAA members at the Hobart Launch



Senator Bilyk is always a great supporter at BTAA events



Canberra member, Nicola Sheehan and Cancer Council ACT Sandra Turner at the Canberra Patient Forum



Mark Hughes and Sandy Nixon at the Hunter Forum



Dianne Legge at the Hobart launch

BTAA secretary, Trish Berman, who led the team who developed the multilingual resources as part of a Cancer Australia grant, was pleased by the reception of the new resources. "The new resources will significantly improve the access to meaningful support for members of Australia's significant CALD (Culturally and Linguistically Diverse) community. Until now there have been no specific brain tumour multilingual resources available in Australia and very few internationally available. The Pathway document and It's Okay to Ask booklet will go some of the way to improving access," she said. Trish is now taking a well deserved holiday after undertaking such a major project over a number of years on a voluntary basis.

The resources are available electronically on the BTAA website. Doctors and Nurse Care Coordinators can request multiple copies by contacting us on our email address. The Pathway document is available as an A3 desktop pad for use in Doctors' rooms. New patients and carers are particularly encouraged to download and print these resources before attending any medical appointments.

Thanks to Tricia Berman (BTAA secretary) who led the project and the project team Dr Jonathon Parkinson (Neuro Surgeon), Dr Danette Langbecker (Research Fellow), Dianne Legge (Brain Tumour Support Coordinator) Sally Payne IBTA Senior Advisor. Janet Micallef, Susan Pitt, Philip Steel and the late Rigoula Roussakis.

COGNO Looks to the Future

The 12th COGNO Annual Scientific Meeting will be held Sunday 27th October - Tuesday 29th October 2019 at the International Convention Centre Sydney, New South Wales, Australia.

The theme for this year's meeting is "The Neuro-Oncology Picture: Now and The Future."

A major focus for this year's meeting is imaging in neuro-oncology. To this end we are delighted to have Associate Professor Ben Ellingson from UCLA, and Professor Ian Law from University of Copenhagen as two of our international guest speakers.

Other areas of emphasis for this year's meeting include updates on glioma surgery, treatment of skull base tumours, and recognition and treatment options for recurrent glioma. To this end we are delighted to have Professor Colin Watts from University of Birmingham and Associate Professor Helen Shih from Harvard Medical School to speak to some of these areas. Additionally Associate Professor Seema Nagpal from Stanford University will provide an update on immunotherapy for glioma.

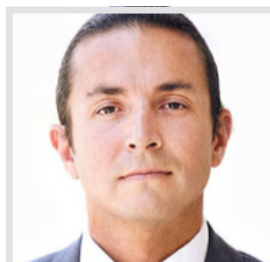
The organisers have also been fortunate to secure a number of local speakers including Professor Richard Harvey (to speak about endoscopic skull base surgery), Associate Professor Kate Burbury (to speak on Tele-trials and their application to Neuro-oncology) as well as many more.

A free patient forum will be held on Sunday 27 October where patients and carers will have the opportunity to meet and hear some of Australia's and the world's leaders in neuro-oncology.

Sessions include:

- Recent advances in MRI for brain tumours
- Recent advances in PET Imaging for brain tumours
- Intraoperative Imaging
- Awake surgery – is its role expanding,
- Endoscopic Endonasal Surgery
- Radiation for Skull Base Tumours
- Re-operation for treatment effect
- Pseudoprogression
- Radiogenomics in glioma
- Palliative care for Glioma Patients
- Rehabilitation for Glioma Patients

You can register for the conference at the COGNO website or the patient forum on the BTAA website.



Associate Professor
Ben Ellingson



Professor Ian Law



Professor Colin Watts



Associate Professor
Helen Shih



Dr Jonathon Parkinson
Convenor

Telehealth "Making Sense of a Brain Tumour" Project.

Being diagnosed with and treated for brain tumour can be a highly stressful experience. Many people find it difficult to understand their illness and feel uncertain and worried about the future.

Researchers from Griffith University are partnering with Cancer Council Queensland and the Princess Alexandra Hospital to evaluate the effects of the Telehealth "Making Sense of a Brain Tumour" Project on emotional wellbeing and quality of life. Delivered via Zoom videoconferencing, the telehealth project is a 10-session psychological support programme for people with a brain tumour and their families, and will be compared to the Cancer Council Queensland's existing psychosocial support service. The project has Ethics approval.

Residents of Queensland aged 18 years or over may be eligible to participate. Family members are very welcome and encouraged to be involved in the study. Participants will receive training and support to learn how to use Zoom on their device.

If you would like to know more about the Telehealth Making Sense of Brain Tumour Project, or would like to take part, please contact the Project Coordinator:

Stephanie Jones
07 3735 3324
stephanie.jones@griffith.edu.au

Avastin Win For Brain Tumour Patients

Susan Pitt

On 28 July the Minister for Health, the Hon Greg Hunt MP, announced August 2019 as the start date of the inclusion of the medication Bevacizumab on the Pharmaceutical Benefits Scheme (PBS) for refractory/recurrent glioblastoma.

Bevacizumab is marketed in Australia by Roche Australia as Avastin®. Bevacizumab (also called by its brand name Avastin) and was listed after intense lobbying by brain tumour groups across the country and submissions from patients. Prior to the listing, patients and families sometimes had to resort to mortgaging their house or crowd funding to pay for the medication, which could cost up to \$20,000. BTAA has advocated for affordable access to this drug since our foundation in 2009.

Bevacizumab binds to and inhibits the activity of a protein present on the surface of cells called vascular endothelial growth factor (VEGF). This VEGF helps cancer cells to form new blood vessels and by blocking the action of VEGF, bevacizumab stops the cancer from developing its own blood supply

This reduces the tumour's supply of oxygen and nutrients, causing it to stop growing and shrink. Drugs that interfere with blood vessel growth are called angiogenesis inhibitors or anti-angiogenics.

While Avastin has been approved for use specifically for use with Glioblastoma Multiforme (GBM) patients it can also be used with other forms of cancers such as advanced non-small cell lung cancer or advanced cancer of the breast, kidney or bowel. The drug is given as a drip into a vein (infusion) once every two or three weeks.

Avastin may not cure a GBM, but does improve quality of life for patients.

Around 1600 Australians are diagnosed with Glioblastoma Multiforme brain tumours each year with an overall rate of around 6 per 100,000 of the population, according to the Australian Institute of Health and Welfare. Of those diagnosed with glioblastoma, only 4.6 per cent will live for more than five years after their diagnosis and this overall survival rate has not improved greatly in the past 25 years.

Mustafa Khasraw, a medical oncologist who works at the Clinical Trials Centre at the University of Sydney, said the cost of the drug had been an added burden for families.

Dr Khasraw said Glioblastoma was a particularly difficult cancer for both patients and their families.

"It's affecting their brain, which means their personality, their existence as a human being, and they lose their ability to think and make decisions," he said.

Dr Khasraw, who has been prescribing Avastin to patients in Australia for 10 years, said it was an important drug even though the drug has not been proven to prolong life.

"In some cases where there is significant disease and swelling, giving them the Avastin can improve their functional performance, that they regain independence even for a short period of time," he said.

"Even if it helps people to regain their dignity, even for a short period of time, it's of great help."

Avastin® can give some people with recurrent glioblastoma a chance to enjoy a level of cognition and function that they would not otherwise enjoy. It works differently to chemotherapy. It is used in several types of cancer to prevent the growth of new blood vessels – to starve the tumour. It is an antiangiogenic therapy. Unfortunately, its early promise as able to improve overall survival in brain tumour patients has not been evident in trials. However, there is now enough evidence to support its use to improve the quality of life for some with recurrent glioblastoma.

BTAA notes the supplier, Roche, seeks to strike a balance between making it easier for patients to access medicines that aren't publicly funded via the PBS, and ensuring subsidised access initiatives are commercially sustainable over the long-term.

In our submission to the PBS, BTAA noted that Avastin® is not without significant side effects, and has not always produced positive outcomes. BTAA understands the Avastin® PBS approval will help patients with relapsed or recurrent glioblastoma that have progressed on, or are intolerant to, temozolomide.

Clinicians know to withhold Avastin® if there is a likelihood of the need for surgery, and neurosurgeons report there is a withholding period if people have had Avastin® before they can operate again. Surgical wounds do not heal due to its antiangiogenic properties.

BTAA's submission also urged the PBS to fast track any immunotherapies that show promise in trials. There are still very few options for glioblastoma patients. Any role of Avastin® in other types of brain tumours is yet to be understood.

BTAA's **Susan Pitt** and **Janet Micallef** represented patients and carers at the announcement, made on a Saturday at Cabrini Hospital, Malvern, Melbourne. Particular thanks to patient **Dr Hugh Weaver** who spoke to both **Minister Hunt** and **Dr Katie Allen**, Member for Higgins, about how Avastin is helping him with symptoms of glioblastoma. **Hugh** was accompanied by his wife **Pam** and supported by Clinical nurse consultant **Emma Daly** and several Cabrini clinicians and researchers.

Australian research funding raising group, Cure Brain Cancer led the push for the listing of Avastin on the PBS schedule. Great work by Annabelle Wilson and team.

Lyn Phelan's AVASTIN BRAIN CANCER SUBMISSION FEBRUARY 2019

Declaration of interest:

My name is Lyn Phelan. In 2009 I was 45, a wife & mother of 3 sons and had a successful career as a practising pharmacist for 25 years.

In February of that year, I was diagnosed with a brain tumour the size of a tennis ball in the right parietal temporal area, Surgery on 11/3/09 resulted in a diagnosis of GBM.

Considering only 22% of brain cancer patients survive more than five years and in those with GBM it is far worse, my survival at this point puts me in an extremely rare category of patient. Being both a pharmacist and a patient also gives me a unique perspective.

My memory and cognitive difficulties meant I was incapable of continuing my career.

My impaired peripheral vision ended my capacity to drive, consequently restricting my independence.

This survival has not been incident free and I've had a further two surgeries in November 2009 and March 2017. The histopathology report following this third surgery revealed the tumour was now testing as a Grade 3 glioma and there were some favourable markers in it, which may explain my longevity.

Last year, a surveillance MRI in August revealed a third recurrence. Two new inoperable tumours.

I've received additional radiation and on-going monthly temozolomide chemotherapy.

In 2013 I underwent training with Cancer Council Victoria to become a Cancer Connect Volunteer.

In this capacity, plus my involvement as a member of the Brain Cancer Support Group run at the Olivia Newton-John Cancer,

Wellness & Research Centre I have spoken with, met and supported numerous people with brain cancer.

Consumer input:

I support the addition of Bevacizumab (Avastin) to the PBS

As a pharmacist I appreciate the process of approving a drug for the PBS is a complex issue, requiring its safety tolerability and efficacy to be highly scrutinised for the safety of the public.

The TGA last reviewed Glioblastoma recurrent Bevacizumab on 18 August 2017 and a review is due by the end of this year.

This is timely, considering it's almost two years since the FDA in USA gave full approval on 12/6/17 to Avastin for the treatment of adult patients with glioblastoma that has progressed following prior therapy.

Over the ten years since my diagnosis I have seen many of my "new" friends agonise over the difficult decision to access this drug, at a huge financial burden to their families, making difficult end of life decisions when perhaps this money could have been better utilised on other aspects of their lives.

Making Avastin available at an affordable price will bring extraordinary hope to many and relieve this burden.

I've seen quite varied outcomes from its use. Some have had an increased quality of life, particularly in the final stages of their illness, due to improvements in neurocognitive function, decreased cerebral oedema and reduced requirements for high dose steroids. This has resulted in delaying the deterioration and extended precious time with their loved ones. Others have experienced significant and debilitating side effects and discontinued its use.

Ultimately, despite treatment with Avastin, they have all died.

The current alternatives do not offer any better outcomes.

I've seen the devastation caused by high dose steroids at first hand. My friend put on 20kg due to the huge dosages required to control her oedema and keep her functioning. She stopped coming to support group because she was too embarrassed and unrecognisable and became extremely depressed and isolated too.

I am not immune. With this latest recurrence, I'm only too well aware that at some point I'll be facing those same dilemmas.

Unlike some, I can afford the cost of Avastin because I have ongoing income protection insurance.

I know only too well, living in the brain cancer community, how fortunate I am to be turning 56 in March and having been there with my husband of 30 years, to raise our three sons to adulthood. Our sons are forging ahead in their chosen careers. Two civil engineers and a pharmacist.

It is heartbreaking that brain cancer is continuing to decimate our young people and people in the prime of their lives and not allowing them to fulfil their potential and live their dreams.

Relieving some of the financial strain experienced by patients and their families and potentially offering a better quality of life at a time when health is declining would provide a huge relief to all concerned.

Thankyou for giving this your consideration.

Lyn Phelan



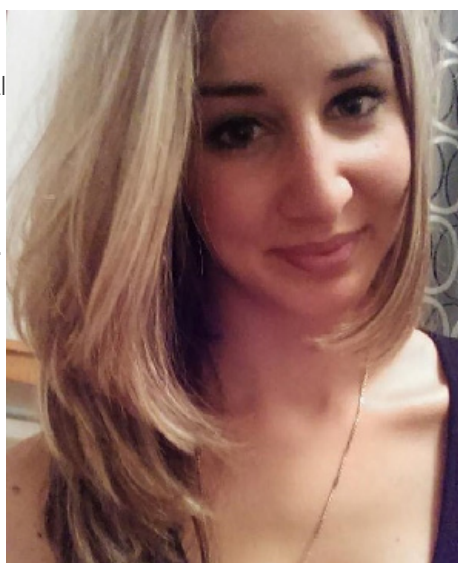
Lyn Phelan at the Brain Tumour Resource launch

Margo's Story

Margo Moloney is a 27-year-old brain tumour survivor from Canberra. Six years ago, she began experiencing symptoms of a brain tumour, such as early morning vomiting, balance issues and head spins.

After a GP referred her for a CT scan, a mass was discovered on her brainstem. Faced with few treatment options, Margo decided to go ahead with surgery under Dr. Charlie Teo, in an attempt to debulk the tumour mass. The surgery successfully debulked a portion of the tumour, however a biopsy confirmed that the remaining mass was a brainstem glioma.

Knowing that the prognosis was quite poor with conventional chemotherapy/radiation options for this tumour type, Margo began looking for alternative options. She came across Dr Herzog's Cancer Clinic in Germany, specialising in integrative oncology and offering a holistic model of care. Here, Margo underwent hyperthermia heat treatment in



combination with low **Margo Moloney** dose chemotherapy and gamma knife radiation, as well as several immune boosting therapies. After three months at the clinic, a follow-up scan revealed some regression of the remaining tumour mass.

Since this time, Margo has had no medication or medical intervention. Instead she has been following a strict therapeutic ketogenic diet specifically for targeting cancer, removing processed food, sugar/carbohydrates and toxins from her environment. After being on the diet for 12 months, a follow-up scan revealed the tumour was regressing to the astonishment of medical professionals. The promising results greatly motivated Margo to stay committed to the keto lifestyle for the past 6 years, with each scan showing further regression. She now has a scan once every two years.

Since the initial surgery which left Margo bedridden for almost 3 months, she has graduated with a Bachelor in Psychology, completed her Masters of Social Work, met and married her husband Joseph, and began working at CanTeen supporting young people affected by cancer. Margo attributes her recovery from cancer to her dedication to a ketogenic lifestyle. She is passionate about helping others on a similar journey, and offers private consultation on implementing a ketogenic diet to help patients fight cancer and reclaim their health and vitality.

CanTeen For All Young People Affected By Brain Tumours

Recently ex-brain tumour patient and Psychosocial Support Worker for CanTeen, **Margo Moloney**, attended the **Canberra Brain Tumour Support Group**, to tell members about some of the services offered for young people by this wonderful organisation. She was concerned that sometimes young patients, their siblings and the children of parents with brain tumours may be missing out on the support activities that are available across Australia from the CanTeen organisation.



CanTeen supports young people between the age of 12-25 years affected by cancer, whether they are a patient themselves or if they have a parent or siblings receiving cancer treatment. They also support young people who are bereaved by cancer. They also provide brief interventions and support to parents affected by cancer, and this support is offered to parents who are either cancer patients themselves or their child is a cancer patient. They offer this support to parents with children aged between 12-25 years.

CANTEEN also offers two online support groups:

Online Support Options

- **CanTeen Connect** is our online support platform for young people – <https://canteenconnect.org.au>
- **CanTeen Connect** for Parents is our online support platform for parents – <https://parents.canteenconnect.org.au>

If you are a young person affected by a brain tumour, or if you are receiving treatment and have young siblings or children, then we highly recommend that you get in contact with **CANTEEN**. They host a wide range of activities and services that offer support for all young people affected by cancer, including brain tumours.

Brain Tumour Patients Can Donate!

When I was diagnosed with anaplastic astrocytoma in 2010, it was a no-brainer that I would donate my tumour to the tissue bank at RPA. Some months later my brilliant neurosurgeon Brindha Shivalingam told me that a medical research project had been able to discover something novel about my tumour's genetic makeup. I feel very privileged and grateful that my tissue is able to be studied.

A year later I saw a Red Cross blood donation van at my local shops and was curious – am I an eligible blood donor?

In June 2018 I saw on the news - Queensland Health revealed that four patients received donor tissue from a patient who had brain cancer. The revelation made national news when it was announced during a review into the state's trouble-plagued heart valve bank. The donor had gliosarcoma, a rare subset of glioblastoma, while all four patients - three babies under 12 months and a young adult - received heart valve tissue. The media was up in arms!

This led me to investigate and clarify the circumstances within which brain tumour patients can donate blood, tissue and organs. This is the result of my findings:

Organ Donation

Almost anyone can donate their organs and tissue. While age and medical history will be considered, people shouldn't assume they are too old or not healthy enough. There's every chance that some of their organs and tissues may be suitable for donation. It is up to medical staff to determine at the time if a person is able to donate organs or tissues.

Having a primary brain tumour doesn't necessarily mean you can't donate. Doctors will decide, when necessary, whether you are a suitable donor. Therefore, if you wish to donate, it is still worth registering your decision.

In summary, primary CNS tumours do not contraindicate organ donation. Cerebral lymphoma and secondary malignancy absolutely contraindicate donation. In each case, the risk to the potential recipient of not receiving a transplant should be weighed against the risk of transmission of donor malignancy. Based on reported data, the risk of transmission is likely to be low, even with high-grade malignancy. Informed consent is required from the recipient and an estimate of the risk of transmission can be based on the SaBTO (Advisory Committee on the Safety of Blood, Tissues and Organs) Guidelines. Craniotomy or other breach of the blood brain barrier does not contraindicate donation, though a ventriculo-systemic shunt may increase the risk of transmission slightly. During the evaluation of a donor with a cerebral tumour, the following should occur during the donor procedure: a thorough thoracic and abdominal exploration with visualisation and palpation of organs and nodes and direct inspection of the cervical lymph nodes and craniotomy site (if present).

Source: Transplantation Society of Australia and New Zealand: Clinical Guidelines for Organ Transplantation from Deceased Donors, 2016

If you wish to become a donor, you are encouraged to register your decision on the Australian Organ Donor Register. It is important that you discuss your donation decision with your next of kin, and that you ask and know their donation decision. Families play a crucial role in the donation process because they are asked to confirm the donation decision of their loved one. The family will be involved in each step of the donation process and be asked to provide vital health information – even if you have registered your decision.

It's easy to join the Donor Register and it takes less than two minutes. To register visit www.donatelife.gov.au/decide - all you need is your Medicare Card number.

Blood Donation

If you are 18-70 years old, healthy and weigh over 55kg, you may be eligible to donate blood. Other criteria for donation include health, lifestyle, travel and medication. You can check your eligibility: <https://www.donateblood.com.au/eligibility#can-i-give-blood>.

Cancer and Blood Donation



Renee Hindson after Neurosurgery (2010) and today

In most cases you can donate again if you remain free of cancer five years after completing treatment. This is to protect your health by ensuring, as far as possible, that the cancer is gone and will not recur. For some cancers (or pre-cancers) of the skin, cervix, prostate, or ductal carcinoma in-situ (DCIS) of the breast, you may be eligible to donate as soon as treatment is complete. However, if you have a history of leukaemia, lymphoma and myeloma, which involve the blood production system, you can never donate blood. This is to protect your health and the health of patients who receive donated blood.

People who have, or have had solid cancers such as brain tumours are not able to donate until five years after the completion of treatment, provided there has been no relapse or recurrence.

Source: Australian Red Cross Blood Service

Don't be disappointed if you cannot donate, because there are other ways you can help. You can spread the word on social media, organise a group to donate blood or become a member or volunteer at the Australian Red Cross Blood Service.

Hair Donation

One of the most distressing side effects of cancer treatments is hair loss. It may occur to some to donate your precious tresses or to hold a shave-for-a-cure fundraising event.

There are a number of organisations and businesses in Australia that accept human hair donations. Variety – the Children's Charity – requires unprocessed (colour treated) hair that is 35cm or longer and all-grey hair is acceptable. Each organisation has a differing set of guidelines for what they will accept so stop before you crop – check the requirements!

Brain and Brain Tumour Donation

Biobanks collect and store various types of clinical samples such as blood and tissue and associated data from consenting donors for use in research.

Clinical samples are collected from patients during surgery for diagnosis and treatment. Any material not required for diagnosis can be stored in a biobank. Researchers with ethically approved projects can then apply to access samples and associated de-identified data for research. There are a number of biobanks around Australia that collect and store biospecimens and data from patients who have been diagnosed with brain cancer to support research into diagnosis, treatment and improved clinical management of brain cancer patients. Any adult or child who has been diagnosed with brain cancer can participate in biobanking.

If you would like to donate clinical samples your first step would be to speak with your treating clinician.

If you require further information please contact Brain Cancer Biobanking Australia at BCBA.org.au.

Renee Hindson



Neuro Nurses at the Newcastle conference.

Neuro-Oncology Nurses Hunter Meeting

The 2nd annual Neuro-Oncology Nurses Network Meeting (NONM) was held on Saturday 20th July 2019 in the Hunter region, bringing together Neuro-Oncology Nurses to meet, collaborate and educate, to better support patients with primary tumours. This meeting was made possible through the collaboration and support of The Brain Cancer Group (TBCG) & the Mark Hughes Foundation.

Marina Kastelan, Neuro Oncology Nurse Practitioner for TBCG was excited to bring Neuro-Oncology Care Coordinators together from around the State to promote awareness, share expertise & increase access to brain tumour specific education. Nurses directly involved in supporting brain tumour patients came from all areas of Sydney and the state, including the Hunter region and the Shoalhaven area. It was great to be able to gather nurses who are passionate about supporting patients and their families. The day also included consumer representatives, our wonderful colleagues from BTAA who offer great support for patients and carers, plus social workers interested in primary brain tumour care.

The day included interactive talks from Clinical Psychologist Cath Adams, who did a great presentation on how we take care of ourselves as Brain Tumour nurses. Palliative Care CNC Kate Munro presented on end of life care and we had a great session by two social workers giving enthusiastic information on accessing the NDIS & Dr Mike Fay, Radiation Oncologist informing us of Radiation Oncology updates & trials.

The purpose of the day was to get enthusiastic, like-minded people together who care for brain tumour patients & to support each other in a role that can sometimes be challenging.

Marina Kastelan

New Website Improves Access

Members of the BTAA committee have been working behind the scenes to redesign and build a new website to replace the existing website which has been in place for the past ten years. The website has a new look, and while it retains all of the former information and functions, it has improved and modernised many of the important operations such as membership, subscription and the handling of donations and registration for events. The new website was launched at the beginning of May to coincide with the publishing of our new multilingual resources.

Much of the development work was undertaken by former committee member Stephen Newman. He was able to use his considerable expertise to look for a suitable web development company and set the parameters for the change over project. Committee member

Peter Ramstadius worked to fine tune the tenders and complete the new website. Peter and Stephen worked tirelessly to improve the web experience for patients and carers as well as streamlining processes for the administration of BTAA.

Fine tuning of the site is still underway, as we work to ensure that there are simple and obvious pathways to the information and support that people require, especially at such a stressful time. The website also provides accurate data so that we can properly target messages to the right people, such as those looking for a support group in their city, carer resources or for medical professionals.

BTAA Chair, Catherine Hindson, says that she is very pleased by the response to the new web page. "I have received many positive comments, and people like the new bright format" she said. "The subscriber and membership section will allow us to operate the BTAA more effectively and efficiently".

If you have a link to a support group, website or story that you think should be included on the website please let us know at btaa.org.au so that we can have it uploaded. We are also keen to include as many patient stories as possible, so get out those computers and start writing.

Peter Ramstadius has worked closely with Web company OPC in Canberra to get the page up and running, sometimes even when in hospital himself. Even though there was a small issue with subscription registrations early in June, leading to lower than normal Brain Tumour Resource Package post outs, this has now been resolved and subscriptions have returned to normal numbers of around 30 per month. Peter says "The new web page has been a big undertaking, but it will provide the flexibility and performance to serve the BTAA well for many years to come and can be expanded as new developments and opportunities arise."

RMH great recognised in the 2019 Australia Day honours



Congratulations to Associate Professor Kate Drummond AM was recognised in the 2019 Australia Day Honours.

Head of Neurosurgery at The Royal Melbourne Hospital (RMH), A/Prof Kate Drummond, was recognised for her significant service to medicine in the field of neuro-oncology, and to community health.

Kate was the youngest and only the fourth female Royal Australasian College of Surgeons (RACS) Fellow to be admitted to practise neurosurgery in 1997. After her medical studies in Sydney, and neurosurgical training at a range of hospitals in Sydney and Melbourne over a period of 10 years, she joined the RMH in 1997. She was appointed Head of Neurosurgery in 2017 and leads the busiest neurosurgery program in Australia.

New resource for Brain Tumour Survivors

Working out how to live your best life with a brain cancer diagnosis can be daunting and difficult. It can be hard to know what to do, what information you need, and who is around to help you.

You may have brain cancer, or have a loved one with that diagnosis. Or you might be a health professional supporting someone in the community to deal with some of the challenges a brain cancer diagnosis can bring. No matter how you came across this strange world of brain cancer, this resource — *Building the Bridge to Life with Brain Cancer* — has been made for you. Building the Bridge to Life with Brain Cancer is a new resource for people living with brain cancer and has been created in partnership with patients, families and neuro-oncology health professionals. Building the Bridge is designed to help navigate the challenges and issues facing people as they begin to re-engage with everyday life after a diagnosis of brain cancer. It is a guide to help people understand some of the long term impacts of the diagnosis, what might help, who might help and how they can take action to live their best possible life with brain cancer.

The resource is available in hard copy and online. To request a copy or download, go to www.buildingthebridge.com.au or phone 03 9496 3315 Dianne Legge Austin Health



Have you or a loved one finished treatment for brain cancer?

Building the Bridge to Life with Brain Cancer — A resource with information and tips to help with getting back to life.

For further info email buildingthebridge@austin.org.au

Building THE Bridge
to Life with Brain Cancer

www.buildingthebridge.com.au



Plan For Tomorrow, Live for Today

Who would you choose to be your voice if for some reason you were unable to tell the Medical Team what health care choices were important to you?

Advance Care Planning is an opportunity to begin a conversation about your health care preferences and what you feel is important for your health care team to know.

An Advance Care Plan is one way of documenting your preferences and important information but more importantly it can help to alleviate the often anxious and stressful decisions having to be made by your loved ones.

A very important question to ask yourself is “Who would I choose to make medical decisions on my behalf, if for some reason I was unable to speak for myself”? In NSW we use the term ‘Person Responsible’ to help identify who that might be in your family and it is not always your ‘next of kin’. Many people often choose to legally appoint an Enduring Guardian who can make decisions about health and welfare on your behalf.

I appreciate this is a tough conversation and most of us don’t want to think about our own death but there are so many benefits that can come from being brave and just starting the conversation. The conversation will usually be an ongoing process and if you have written your advanced care plan already, revisit it regularly to ensure your preferences haven’t changed.

A copy can be given to your General Practitioner and/or a member of your health care team. You can also keep a record on ‘My Health Record’ and of course most importantly give your Person Responsible a copy and tell members of your family.

Plan for Tomorrow while Living for Today.
Kate Munro, End of Life Care Coordinator
Hunter New England Health

<https://www.advancecareplanning.org.au/individuals>

<http://planningaheadtools.com.au/advance-care-planning/>



Please join us for the

5th Annual White Pearl Ball

In aid of brain cancer research and supporting
The Brain Cancer Group
From Care2Cure

Saturday, 9 November 2019
6.30pm

Grand Ballroom
Hyatt Regency Sydney
161 Sussex Street
overlooking Darling Harbour

\$250 per ticket
Early bird special by 1/8/2019 – \$235 per ticket

Formal/black tie

To purchase tickets or donate:
www.whitepearlfoundation.org

For all enquiries:
suzane@whitepearlfoundation.org
or 0418 238 723



WHITE PEARL
FOUNDATION
Brain Cancer Research Funding





Brain Cancer Patient Education and Support Forum

All patients, carers and their families are most welcome!

The patient education and support forum is an unique opportunity for patients, families and their supporters to hear from international and national experts in brain cancer treatment, research and support. Talks will be followed by a Q&A session where attendees can ask the experts questions. This event is held in conjunction with the annual COGNO scientific meeting and conference.

When

27 Oct 2019 9:30 am - 2:15 pm

Where

Convention Centre ICC Sydney -
Darling Harbour Sydney

Cost

FREE

[Book your ticket on the BTAA website now](#)

Event registrations close

26 Oct 2019 5:00 pm

(Hosted by NSW Neuro-Oncology Group (NNOG), Brain Tumour Alliance Australia (BTAA), Cooperative Trial Group for Neuro-Oncology (COGNO))



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

SPREAD THE WORD!

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

1800 857 221
www.btaa.org.au



Brain Tumour
Alliance Australia



@BrainTumourAA



Search 'BTAA' for
various videos

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