



BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

THE OFFICIAL BTAA NEWSLETTER

BRAIN TUMOUR ACTION MONTH EDITION

MAY 2019 EDITION

BTAA.ORG.AU

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INSIDE THIS ISSUE

DIARY DATES

LETTER FROM THE CHAIR

THE BRAIN CANCER GROUP
WORKS FOR BEVACIZUMAB
PBS MEDICATION

SUPER AND TPD INSURANCE

2018 COGNO LATEST
RESEARCH

SYDNEY SUPPORT NETWORK

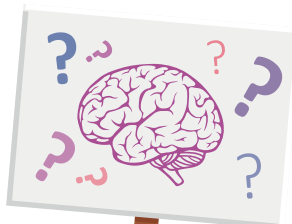
UNIVERSITY OF CALIFORNIA
SAN FRANCISCO RELEASES
NEW CARE GIVER RESOURCES

HUNTER BRAIN
CANCER FORUM

It's **okay** to ask
Questions to ask your healthcare team about
your **brain tumour** and treatment



Está **bien** preguntar
Preguntas para hacerle al equipo a cargo del
cuidado de su salud sobre el **tumor cerebral**
que tiene y sobre el tratamiento



El proyecto Supporting People with a Brain Tumour
(Ayuda para personas que tienen un tumor cerebral) es
una iniciativa para otorgar subsidios de Supporting People
with cancer (Ayuda para personas que tienen cáncer) de
Cancer Australia, financiado por el gobierno australiano.

MULTI-LANGUAGE SUPPORT RESOURCES LAUNCHED



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

Executive members

Chairperson: Catherine Hindson

Vice chairperson: Philip Steel

Secretary: Trish Berman

Assistant Secretary:
Billy Williams

Treasurer: Pat Wynn

Ordinary Committee members

NSW Alice Parsons

VIC Janet Micallef

ACT William Williams

QLD Pam Hubner

NSW Michael Parsons

Public Officer: Tricia Berman

Specialist Advisers:

Denis Strangman, Matthew Pitt.

Currently the following committee members are looking after these focus areas:

Support: Catherine Hindson

Inform: Philip Steel

Represent: Susan Pitt

Connect: Janet Micallef

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.

This magazine is produced for the **May Brain Cancer Action Month** and we hope you will be able to attend some of the events we have detailed in this issue.

Since our last official BTAA magazine the **11th Cooperative Trials Group for Neuro-Oncology (COGNO)** was held in Brisbane in October 2018. Brain Tumour Alliance Australia and the Mark Hughes Foundation sponsored **Dr Terri Armstrong**, a Senior Investigator with the Neuro-Oncology Branch of the National Cancer Institute in the USA to be a guest speaker. While in Australia, Dr Armstrong also addressed a Patient Forum in Brisbane at the Cancer Council on "Be your own best Advocate". The podcast of all speakers; **Dr Po Linglis, Caroline Sandler, and Lee Cubis**, is available on the Qld Cancer Council website. I would like to thank **Clare Howard and Anna Gordon** at the Qld Cancer Council for their direction and assistance in making this forum possible and a success.

Post COGNO educational sessions were held in Sydney and Melbourne for Medical, Nursing and Allied Health Professionals who were unable to attend COGNO. In Sydney the speakers were; Associate Prof. Mustafa Khasraw, Prof. Susan Chang, and Dr Armstrong. In Melbourne the speakers were; Dr Laurence Cher, Dr Armstrong, and Dianne Legge. The Sydney event was hosted by The Brain Cancer Group and coordinated by Marina Kastelan. The Melbourne function was held at the Olivia Newton-John Cancer and Wellness Centre and coordinated by Dianne Legge.

In November, I represented the BTAA at the **23rd Annual Meeting and Educational Day of the Society for Neuro-Oncology (SNO)** in New Orleans. It was a huge 4 1/2 day conference with concurrent sessions running from 7am till 7.30 pm, and a choice of 7 tutorials, and educational sessions at lunchtime each day. In the afternoon there was a choice of 4 concurrent sessions occurring, making it difficult to choose from such a wealth of up to the minute information. There was a good contingent of Australian clinicians and researchers at SNO and I enjoyed being able to say hello to fellow Aussies among the 2350 attendees.

It was inspiring to hear of the research and trials being reported on and interesting to hear American Oncologists in the audience saying they wanted to have trials available to them in their small centres. While some of the trials showed promise the results were in the very early stages.

There was a big interest in the session on Meningiomas.

Many papers were presented to a large audience and the moderator concluded that SNO would continue to present the research and clinical trials in this kind of brain tumour.

By now many of you will be looking forward to the BTAA **monthly e-news** that we have been producing since mid 2018. We have had lots of reports that the articles are well received and on point. A big thank you goes to **Steve Newman** who spends many hours researching and producing BTAA e-news. We welcome articles and news items that you would like to distribute to our subscribers. Please contact us through enquiries@btaa.org.au if you wish to contribute.

BTAA and several of our committee made submissions supporting the Roche submission to the **Pharmaceutical Benefits Advisory Committee (PBAC)** for **Avastin** to be listed on the Pharmaceutical Benefits Scheme (PBS) for the treatment of relapsed or recurrent glioblastoma. This submission will be considered at the PBAC's March meeting. Approval of Avastin by the PBAC will relieve the enormous financial burden that many families face when they are offered this drug.

During May we will be launching **new brain tumour resources developed in 10 different languages**. This enormous project was led by BTAA's secretary, Tricia Berman, and she was supported by a Steering Committee comprising **Dr Langbecker** (U QLD), Diane Legge (The Austin), **Dr Jonathon Parkinson** (Neuro Surgeon), and **Sally Payne** (IBTA), and the project team of **Janet Micalief, Susan Pitt, Philip Steel** and the late **Rigoula Roussakis**.

May will be a very busy time for us with many events including the launch of our new brain tumour resources and patient forums. On the next page is a list of activities being held during May's Brain Cancer Action Month.

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.

May 2019 Events Calendar

Event	State/City	Date/Time	Address	RSVP
Brain Tumour Patient Forum and BTAA Multicultural Brain Tumour I launch	Sydney NSW	3rd May 2019	Wesley Conference Centre 220 Pitt Street Sydney 2000	BTAA website or call 1800857221
Brain Tumour Patient Forum	Canberra ACT	6th May 10-2pm	Canberra Hospital Yamba Drive Garran 2605	BTAA website or call 1800857221
BTAA Multicultural Brain Tumour Launch	Canberra ACT	6th May 6-7.30pm	Commonwealth Club 25 Forster Crescent Yarralumla 2600	chair@btaa.org.au or 0412041245
Brain Tumour Patient Forum	Hobart TAS	7th May 2-4.30pm	Tasmania Club 32 Macquarie Street Hobart 7000	BTAA website or call 1800857221
BTAA Multicultural Brain Tumour Launch	Hobart TAS	7th May 2.00-4.30	Tasmania Club 32 Macquarie Street Hobart 7000	chair@btaa.org.au 0412041245
BTAA Multicultural Brain Tumour Launch	Adelaide SA	8th May 6-7.30pm	Naval, Military & Airforce Club of SA 111 Hutt Street Adelaide 5000	BTAA website or call 1800857221
Brain Tumour Patient Forum	Adelaide SA	9th May 5.30-8 pm	Cancer Council SA 202 Greenhill Rd, Eastwood 5063	BTAA website or call 1800857221
3rd Annual Hunter Brain Cancer Forum	Newcastle NSW	10th May 9.30-2.30	New Lambton Bowling Club	enquires@markhughesfoundation.com.au or Sharron 40377400
Shitbox Car Rally Fundraiser	Perth WA	17th May 8.00pm	TBA	TBA
BTAA Multicultural Brain Tumour Launch	Melbourne Vic	21st May	RACV City Club 501 Bourke Street Melbourne 3000	chair@btaa.org.au or 0412041245
BTAA Multicultural Brain Tumour Launch	Brisbane Qld	22nd May	The Queensland Club 19 George Street Brisbane 4000	Chair @btaa.org.au or 0412041245
Patient Forum	Brisbane Qld	23rd May	Cancer Council QLD 553 Gregory Terrace, Fortitude Valley	BTAA website or 1800857221
Mel's Go Grey In May Dinner	Bathurst NSW	25th May	Bathurst Panthers 132 Piper Street, Bathurst	Club reception 0263300600
Patient Forum	Melbourne Vic	14th June	TBA	TBA

NEW BRAIN TUMOUR SUPPORT CALD RESOURCES WILL ENSURE THAT MULTICULTURAL AUSTRALIA HAS THE ACCESS TO THE SUPPORT IT NEEDS

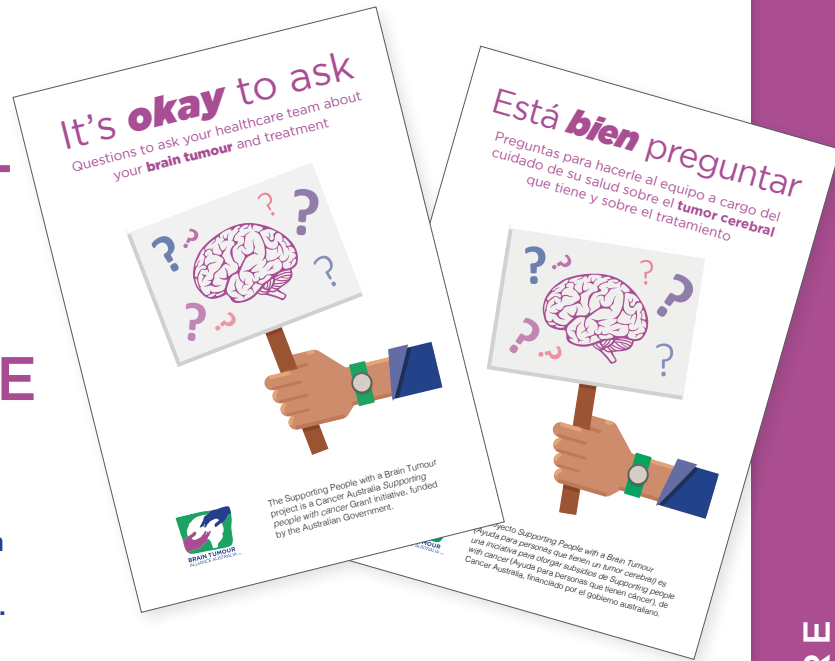
A major initiative from the BTAA, supported by Cancer Australia, has developed new resources in 10 languages to support patients and carers from Culturally And Linguistically Diverse backgrounds. The resources have been developed by some of Australia's leading experts in patient care and support, after close consultation with community groups. The new resources will be launched in May, and will be available as translated documents, videos, and online.

Project Background

In 2016, Brain Tumour Alliance Australia was awarded funding for its Supporting People with a Brain Tumour project to develop new resources for brain tumour patients, their carers and families including for CALD (culturally and linguistically diverse) communities. The Supporting People with a Brain Tumour project is a Cancer Australia Supporting People with Cancer Grant initiative, funded by the Australian Government.

A Steering Committee comprising Dr Danette Langbecker (Research Fellow, The University of Queensland), Dianne Legge (Olivia Newton-John Wellness & Research Centre - Austin Health), Dr Jonathan Parkinson (Neurosurgeon & Spinal Surgeon), and Sally Payne (Senior Advisor, IBTA) oversaw the project. It was assisted by a Project Team comprising Patricia Berman, Catherine Hindson, Janet Micallef, Susan Pitt, Rigoula Roussakis, and Annabelle Wilson.

The two new documents produced through the BTAA project will help patients and their families following the diagnosis of a brain tumour. In developing the new documents, the Steering Committee were concerned about how difficult it is for patients and their families to take in all the new information at a time of great stress. This difficulty is even more pronounced for culturally and linguistically diverse patients and their families.



QUÉ ESPERAR EN EL FUTURO

WHAT TO EXPECT

- ¿Cómo cree usted que voy con el tratamiento?
- ¿Es probable que el tumor vuelva después del tratamiento?
- Si es probable que el tumor vuelva, ¿cuánto tiempo tardará en volver?
- ¿Qué probabilidades hay de que se cure el tumor?
- ¿Cuánto viven normalmente las personas que tienen este tipo de tumor? ¿Cuál es la mayor cantidad de tiempo que vivió una persona que usted conoce?
- ¿Cuáles son mis probabilidades de supervivencia?
- ¿Puede volverse más agresivo mi tumor en el futuro?
- ¿Puede mejorarse solo el tumor? ¿Empeorará si no se lo trata?
- ¿A qué le prestará atención para predecir qué pasará en el futuro?
- Si el tumor no se puede curar, ¿qué puedo esperar en el futuro? ¿Cómo serán mis mejores y mis peores días?

NOTES

11

脑瘤病情简介

该脑瘤病情简介可帮助您与您的治疗团队讨论您的肿瘤类型、分级、位置和治疗方案。

肿瘤类型:

肿瘤分级:

1 2 3 4

低级 高级

重要的肿瘤特性:

可能造成的副作用:

治疗方案:

☐ Surgery:

☐ Biopsy ☐ Partial resection ☐ Major Resection ☐ None

☐ 放疗:

☐ 化疗:

☐ 临床试验:

☐ 癫痫管理:

☐ 其他药物:

脑瘤治疗过程

本计划旨在帮助您应对脑瘤治疗的过程。

护理人员的联系方式

添加与您有关的其他联系人 -

神经外科医生

姓名: 电话:

肿瘤内科医生

姓名: 电话:

放射肿瘤医生

姓名: 电话:

护理协调员

姓名: 电话:

家庭医生

姓名: 电话:

工作时间以外求助联系人

姓名: 电话:

姓名: 电话:

姓名: 电话:

获得帮助的途径

BRAIN TUMOUR ALLIANCE AUSTRALIA (澳大利亚脑瘤联盟)

网络支持、信息、宣传

bttaa.org.au | Ph: 1800 857 221

CANCER COUNCIL (癌症协会)

癌症信息和支持

cancer.org.au | Ph: 13 11 20

CANCER AUSTRALIA (澳大利亚癌症协会)

癌症治疗指南、癌症治疗和资源

cancer.gov.au

CAREERS AUSTRALIA (澳大利亚护理人员协会)

为家人和护理人员提供支持

careersaustralia.com.au

Ph: 1800 241 636

AUSTRALIAN CLINICAL TRIALS (澳大利亚临床试验协会)

临床试验网络

australianclinicaltrials.gov.au

What are the two new documents?

To assist patients and their families, BTAA has produced a new document called My Brain Tumour Pathway. It contains a series of columns where information about the patient's brain tumour can be recorded. And information about the treatment and who to contact can also be recorded. The document can be filled in with the help of the treating physician, surgeon and/or brain tumour nurse. It gives patients a hard copy record of their diagnosis, the treatment that they will be having, and those to contact about aspects of their journey. The document is available in 10 languages in addition to English. The document is only one page and can easily be printed from the BTAA website.

To assist patients and their families to feel more confident in asking questions about their brain tumour, a new up to date version of the 2008 document It's Okay to Ask has been developed. As the booklet says, 'Don't be afraid to tell your doctor how much or how little you want to know'. It is a small 36 page booklet which both asks questions and leaves space for the patient, family member or carer to write the answer. The document can be printed from the BTAA website in several languages. Questions are grouped in the following areas:

- diagnosis
- what you can expect in the future
- symptoms and changes
- the healthcare team
- support
- treatment and management
- what to expect after treatment

The documents and videos are in 10 languages:

- Arabic
- Chinese - Simplified and Traditional
- Dari
- Filipino
- Greek
- Hindi
- Italian
- Vietnamese
- Punjabi
- Spanish

Brain Tumour Patient Video also available to CALD communities

The 'A Common Path' suite of cancer support and advice videos have been developed by NEMICS (The North Eastern Melbourne Integrated Cancer Service, or NEMICS, is a clinical network) for people who have been newly diagnosed with cancer. As part of the project, BTAA has translated the NEMICS video on 'High Grade Glioma' into 10 languages. Three brain tumour patients speak about their journey following diagnosis. The translated videos will be accessible on the BTAA website in May 2019.

Who helped BTAA to produce the new documents?

In addition to Cancer Australia, the project Steering Committee and the Project Team, BTAA would like to particularly thank the brain tumour patients, carers, and family members who contributed to the project by participation in Focus Groups held in Brisbane, Sydney and Melbourne in August/September 2017 to give feedback on the resources.

BTAA would also like to acknowledge the major contribution of Dr Danette Langbecker who developed the initial document It's Okay to Ask in 2008 and the School of Public Health, Queensland University of Technology, who published the initial booklet.

Where are the new documents going to be available?

The new documents will be available on the BTAA website from 3 May 2019.

They will be launched at Patient Forums in capital cities across Australia during May 2019 - Brain Cancer Action Month. Check the BTAA website to register your attendance at one of the Patient Forums in May 2019. There is no cost but you need to register for catering purposes.

Some members of the Steering Committee will be participating in launches of the new documents:

- Dr Parkinson will participate in the launch of the new documents on 3 May 2019 at the Sydney Patient Forum at the Wesley Centre during Brain Cancer Action Month Patient Forum.
- Dr Langbecker will participate in the launch of the new documents in Brisbane May 2019 during Brain Cancer Action Month.
- Dianne Legge will participate in the launches of the new documents in Melbourne and Hobart (7 May 2019).

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



Sally is an IBTA Senior Advisor based in Sydney, Australia.

Sally has been assisting the International Brain Tumour Alliance (IBTA) since 2006.

Sally is an Associate Dean of Studies in an academic institution and is responsible for managing the quality of the teaching and learning.

Sally's sister, Arianne, was diagnosed with a brain tumour in 2005 at age 38 and passed away, at age 43, in September 2011. Sally assisted in caring for Arianne and is very aware of the challenges associated with brain tumours.



Dr Danette Langbecker is a Research Fellow at the Centre for Online Health at the University of Queensland. Her program of research encompasses psycho-oncology and digital health, investigating how best to support cancer patients and their families, with a focus on people affected by brain tumours, and new technologies such as telehealth,

mobile health and online interventions, to improve models of care for people with a range of conditions.

Digital health studies Danette is leading include investigating the implementation of telehealth to deliver allied health services to children in schools, forensic mental health assessments for youth in the criminal justice system, and geriatric assessments for persons with dementia living in rural and remote areas.



Dr Jonathon Parkinson graduated from medicine at the University of Sydney in 1998. He undertook his advanced neurosurgical training at Royal North Shore Hospital, John Hunter Hospital, Sydney Children's Hospital, Prince of Wales Hospital and Royal Prince Alfred Hospital. During his specialist training, Dr Parkinson completed a Doctor of Philosophy (PhD) at the Kolling Institute of Medical Research,

University of Sydney where he studied the molecular biology of brain tumours. As well as his surgical work, Dr Parkinson is continuing his brain tumour research.

He is the current chair of the NSW Oncology Group (Neuro-oncology) as well as being on the management committee of the Australasian Neuro-oncology group, COGNO (Co-operative Trials Group for Neuro-oncology). Dr Parkinson is an important member of the multi-disciplinary team managing brain tumours across both the North Shore campus and on the Central Coast.



Dianne Legge, BAppSc(OccTher) MAppSc(Res) is an occupational therapist and qualitative researcher working as the Brain Tumour Support Coordinator at the Olivia Newton-John Cancer Centre – Austin Health, Melbourne. Dianne's research and clinical interest is in how people accommodate the disruption and live a good life after a brain cancer diagnosis. She is actively involved in the brain tumour support community in Victoria

and nationally through BTAA and COGNO, and is passionate about resourcing people to live their best life possible. She is currently the Lead for a Victorian Cancer Survivorship Project.

New Book: Jack's Story

The book, Jack's story, is about Jack, his family, diagnosis, struggle and death.

It is about his life and particularly the last 22 months. It is a love story and a tragedy and tells about an ordinary family who waged an extraordinary battle against a disease that has no cure. We never stood a chance. It is a story of hope and promise, as well as loss and despair, and finally, tragedy.

It is about a very brave young man that I had the pleasure of sharing 21 years with because that is all that he had to share, 21 years. I was with him when he took his first breath and I was with him when he took his last. One was a moment of exquisite pleasure and the other was a moment of unimaginable pain. He gave life, and particularly the last two years, his best shot. He never stopped smiling; never gave up; never said no more.

He was diagnosed with glioblastoma multiforme (GBM) on a cold, wet and wintry 8 July 2016. He died on 15 April 2018. He was given 12 months. We got 22 months. So, I asked, how do I make something good come out of this?

I promised Jack I would save his life and I would write a book. I kept one promise. And if the book was successful, I could use the money to find a cure for brain cancer ... Jack liked that idea.

As time evolved, his natural brilliance was suffocated by the disease, drugs, surgeries and radiation. "I am now the dumbest person in the family" he lamented. He was probably the smartest, but over time the cancer stole everything. Kill the tumour and a lot of that brain function would return but not all. There were bits missing because of surgery and radiation but without that, he wouldn't have lasted 22 months and his quality of life would have been severely compromised. Catch 22.

The book is my way of remembering, reminiscing and maybe I can help save a life and the universe will be in harmony again. We would have given our lives for Jack in a heartbeat.

We have life and Jack doesn't, so we have to embrace what he lost.



Brain Tumour Patients Need to Check Super Based Insurance

Recently some of our members have had success in making claims with their Superannuation funds as a result of effects of their brain tumours. These claims were successful despite initially being rejected by the insurers, so it may be worthwhile to investigate what your superannuation policy has to offer.

Most superannuation fund members will be unaware of largely silent insurance policies that are often attached to these funds. If you're unable to work, or injured in the course of your employment, or become ill as a result of it, you may be eligible for additional cover and benefits. This is because most superannuation schemes also include insurance for total and permanent disability which will entitle the holder to a lump sum payment in the event that they are unable to work.

You may not have been aware of having this cover because when you sign up with a super fund, the insurance cover is often included as a default. In addition, super schemes also typically offer income insurance, which can be opted into as an extra monthly premium, payable along with your super contributions. If you are covered by super, you are likely to have active insurance cover in the event you are totally and permanently disabled. This insurance could involve a lump sum compensation payment, which can be kept in addition to WorkCover entitlements.

You could be eligible for a Total and Permanent Disability compensation claim if you can show you're unable to do your normal job or any other work related to your training and experience. This doesn't mean you're unfit for all work, it means you're unable to do the work fitting your area of skills and expertise. For example, if having a bad back stops you from working in your normal construction job, you can usually make a TPD claim, even if your doctor says you're fit for another kind of employment, such as office work.

Melbourne based members from GreyMatters, report that legal firms such as Ryan Carlisle Thomas Lawyers (RCT) in Melbourne will act for brain tumour patients under a "No Win No Fee or Expenses" policy, on fees and out of pocket expenses, and will waive their fees if you don't win a case that they have agreed to fund, and pick up the costs of your out of pocket expenses. Out of pocket expenses are counted as medical reports, court fees and many other expenses that other firms would typically require you to pay in the event the case was lost. If they don't think you have a reasonable chance of winning, they will advise you not to proceed.

While the BTAA is not in a position to provide a legal opinion on any case, and is not able to recommend any legal practice or offer, we do encourage brain tumour patients or their carers to investigate their eligibility for superannuation based insurance. If you engage a legal firm you also need to be very clear about the terms of the agreement, the financial settlement and any liability you may have if the action fails.

The BTAA has no link with Ryan Carlisle Lawyers, however our Grey Matters members have found that they have experience and success in the area of brain tumour actions.

We Need Your Help

The BTAA provides support for brain tumour patients, families and carers across Australia. Our 24/7 telephone support service provides immediate support, information and connection for the newly diagnosed.

Comprehensive information packs are distributed to hundreds each year for free. Our patient forums give members of the brain tumour community access to world brain tumour experts. Support groups and support group leader training are nurtured across Australia. Links to up to date information are available on our web page.

All of this achieved through the hard work of our dedicated volunteer members, but we do need funds to cover the everyday operational expenses of the BTAA such as support resources, postage, printing, materials, telephone costs, venues, web hosting, and training.

BTAA does not fundraise but focuses its energy on providing support to those in need.

Our support work has been possible with donations and we thank **Martin Moses, Sharon Moloney, Michael Scott, Edith Williams, Sue Cuttler, Tanya Ponspord, Karin Simpson, Barbara Walsh, Robin Baker, Julie Pham, Nicola Sheehan, and Roy Menzie** for their recent donations to BTAA. In addition, thank you

for donations in memory of **Robyn Hillaker** and **Michelle Farran**.

Your contribution will ensure every patient, family and carer has the support they need.

Go to

www.btaa.org.au/donations

Direct debit

BSB 062 900

Account 10603153

Email btaa@shout.org.au for a tax receipt

Cheque

BTAA
Box 717
MAWSON ACT 2607

Rachael's Story

I never expected my husband to propose marriage when he did. It was the afternoon of June 15th and around us there was the beeping of IVs and the murmurings of visitors. Every now and then a nurse would speak and a food trolley would rattle as it moved down the corridor. But all I could see was John's face and the tears pouring down it. Moments before I had told him that MRIs had shown two brain tumours.

He just kept shaking his head as I told him, telling me that he loved me more than anything and that we'd fix this. This beautiful, solid man who was always my strength sobbed in my arms, asking me questions I couldn't answer.

How did we end up here? Three days before John called an ambulance as I was extremely ill and hallucinating, doctors ran tests and settled on a diagnosis of viral meningitis. But the CT scan had showed something that required more investigation. Three MRIs later they confirmed a meningioma in the Clivus region and a probable grade 2 Ependymoma intramedullary at C2/C3.

Eight months later I've learnt more than I care to know about brain tumours and the medical terminology that goes along with. I feel like I've landed in a foreign country where I don't know any of the language or culture. Ependymomas only occur in approximately 1/1,000,000 so assistance and knowledge is minimal in Australia.

The diagnosis has affected all of my loved ones in different ways. For my 17 year old daughter PJ, she decided that doing something proactive would help. She settled on a trivia night which raised \$8300 for BTAA. We're incredibly proud.

On March 4th I will be flying to the US with my 16 year old daughter Saskia. While there I'll spend several days being assessed at a clinic run by CERN (Collaborative Ependymoma Research Network) in Maryland. They are the only organisation in the world currently running active trials on adults with Ependymoma. I'm going there for answers, but mostly I'm going there to find some hope.

Rachel's daughter Piper Jade, organised the "Pick Your Brains": trivia night for BTAA in November 2018. It was a family and community effort that raised \$8,300. The BTAA would like to extend our thanks to Piper Jade, Rachael and the whole family and all of those who supported this fantastic fundraising event. Special thanks to Mark Parton, who took time from his busy schedule as an ACT MLA to comper the night, and Colin McCulloch from Bartercard



Rachel, second from the left

The Brain Cancer Group Works for Bevacizumab PBS Medication



The Brain Cancer Group

From Care2Cure

In a collaborative effort, The Brain Cancer Group, From Care2Cure, has joined with other Not-for-Profit groups to endorse a PBAC listing of Bevacizumab on the PBS for the treatment of relapsed glioblastoma (Grade IV glioma, GBM). As a Group who have funded dedicated Neuro-Oncology Care Coordinators for over 10 years, TBCG have an intimate connection to a range of primary brain cancer patients. This close insight has identified concerning variation in clinical care.

TBCG has written a submission to the Pharmacy Benefits Advisory Committee to consider the inclusion of the medication Bevacizumab on the PBS for the treatment of relapsed GBM.

The medication which is currently not included on the PBS schedule, has been shown to increase progression-free survival and improve the lives of people living with the disease. However, at a cost of approximately \$3,600 to \$4,600 per dose, access to the medication is out of reach for many Australians.

At present, there are no adequately efficacious therapies listed on the PBS for the treatment of relapsed GBM.

Bevacizumab is internationally recognised as a standard of care in this setting, has TGA approval and is considered to be the most useful treatment option in many patients with GBM. It is hoped that with inclusion of the medication on the PBS, patients will have an increased likelihood of finding an effective and well-tolerated treatment that suits their individual circumstances.

In other news The Brain Cancer Group researcher Dr Amanda Hudson has been awarded The Olivia Addison Research Grant of \$100,000, in memory of Olivia Addison. Dr Hudson will be researching the ability to repurpose old drugs as new treatments for brain cancer. This funding, which has been generously provided by Mark Hughes Foundation, was awarded through Hunter Medical Research (HMRI), and is a further demonstration of our research team's ability to attract funding to help in our mission 'From Care2Cure'.

BENDOC -DELEGATE Mourns Michelle Farran's Passing

Michelle lived a very full life, though one tragically cut short. Michelle had a razor-sharp intelligence. She was capable of immense empathy and sought out and supported the underdog, the misfit and the different. She loved being in the bush – it refreshed her soul and inspired her creative mind. Traditional crafts were a challenge to her love of learning and she was never happier than when tanning a hide or plaiting rope. She was an active scout who in the week before she became ill, kayaked down the Murray for five days. Her musical talents were often on show and culminated



in her album 'Rockton' from which songs for her celebration have been taken. **If there was a stage and singing going on, Michelle wanted to be there.**

Michelle was a fantastic educator. She had an affinity for what the purpose of a lesson was and would draw elaborate pictures to inspire her class to understanding a concept. She devoured knowledge about how the brain works and how

children develop and used this to work out programs for students with special needs.

Michelle loved this area and gave out to her community in so many ways – as deputy controller of the Bendoc SES, as a Regional Commissioner for Scouts, on numerous boards and committees, with the Rotary Community Choir and 23 years as a parent at Monaro Dance Centre.

On 3rd February 2018 Michelle had a seizure and was diagnosed with Stage 4 Brain Cancer. Over the past year she had to cope with slowly losing her abilities. She kept her spirits; when she found she could no longer read she simply listened to audiobooks. The hardest thing was not being able to 'talk in English' anymore. She fought hard despite the increasing discomfort and passed away on Sunday 17th February shortly after midnight surrounded by family.

She will be sadly missed by all those whose hearts she touched.

Editors note: Members of the tiny rural community of Bendoc located near the NSW /Victoria border donated over \$1200 to the BTAA at Michelle's Celebration of Life.

Canberra couple's Christmas lights display boosts brain cancer support



The creation of a spectacular Christmas lights display by a Canberra couple has given a much needed boost to the work of a national support network for brain cancer patients and their carers.

In presenting a cheque for \$3,300 to the Chair of the Brain Tumour Alliance Australia (BTAA), Katherine Hindson, the Harrisons said they hoped this support would help extend the BTAA's work of providing crucial and timely support and services to those affected by this disease. A further \$558 was donated directly to BTAA by visitors to the light display.

"We feel that the lighting display brings happiness to families at Christmas and it is our way of giving support to others in our community suffering from brain cancer or who are disadvantaged in other ways" said Kay and Roger.

A total exceeding \$8,000 was received from donations made by visitors to the display, including the sale of Christmas craft items that had been mostly made by Kay and a small group of helpers during the year.

Kay and Roger Harrison have also directed funds from the Christmas lights display to an Orthopaedic Centre for children in Ghana, the Cancer Council ACT, the planned Wellness Centre at the Canberra Region Cancer Centre and the Chamberlain Foundation.



Leonie's Story

Editor: This is an edited version of the full story available on our website.

My children spent their lives waiting around emergency rooms or at my hospital bedside visiting me, while I recovered from another round of neurosurgery or multiple seizures. These needed to be controlled or the serious depression I would fall into because as a young mum I could no longer be independent and be well enough to care for my children.

I remember once when my daughter was about two, her dad brought her to visit me in hospital I was recovering from a craniotomy and a fenestration, where my neurosurgeon tried to pierce open the huge cyst I had. My surgery three weeks before had failed, as a shunt that was inserted could not drain the pressure off my cyst, which was pressing on my brain.

I spent a lot of time that year in an out of hospital and I would sometimes wake up from a visit I had missed with the children.

Nobody in the eighties could tell you the outcome following brain surgery. I found I would have outbursts and a complete personality change. My outbursts would happen when I was under stress from being so physically exhausted and in pain that my brain couldn't cope I found it hard to concentrate so I couldn't hold a conversation well at all. I was no longer allowed to drive.

Due to my personality changes and the stress of being in an out of hospital, and the bills mounting up from all the trips to and from Melbourne, parking fees, specialist bills, my husband and I broke up because we couldn't cope. One time when I was so unwell and unable to take my children to school the school had family services come to see us. The problem was, as I had no family to help as my elderly mum was

dealing with my adult sister who had autism and lived interstate. I had also become withdrawn from society. I'd be scared of having a seizure down the street, and I was taking so much anti-seizure medication to control them I was continually groggy and I hated having to take it.

Leading up to my seventh lot of neurosurgery at this stage in my life, I realised there would be more surgery and throughout the remainder of my life as I got older recovery was getting harder. I had up until now always bounced back after my surgery's to release pressure from my brain. But now I wasn't bouncing back as well any more.

I have located twenty three patients here in Australia and the problem is a lot of them or their families are going through all these issues. We desperately need a Support group here in Australia, and this is my aim, to find someone to help us with research for further awareness of this disease. There are some heartbreaking situations among these families and they are not getting the medical attention and support networks needed. We are all over Australia, and would like to meet twice a year to organise support networks for patients, families and carers.

This has been organised at the Melbourne Brainlink Offices for our annual meetings but I'm looking for someone or an organisation who could help us with funding for their travel and accommodation. Some of our children are mentally delayed or are wheelchair dependent, a lot of us have bladder and bowel issues and mental health issues, personality changes, coordination issues the list goes on. We need advocacy and we need help.

If you are a Patient, Family Member and/or Carer you can find support from these Facebook pages: Arachnoid Cysts or Arachnoid Cyst Awareness Around The Globe.

If you are interested in joining our Australian Support Group; contact 0419 993362

PERSONALISED MEDICINE A RIGHT FOR ALL AUSTRALIANS

As early as 2004 at the World Cancer Congress in Dublin presentations about personalised medicine based on genetics of breast and prostate cancers were made. The breast cancer lobby pushed quickly for drugs that acted on HER2 positive breast cancers and as a result can now be categorised as to their potential for response by new drugs.

Meanwhile, the breast cancer lobby was pushing for drugs that acted on HER2 positive breast cancer. One that became popular was trastuzumab. Patients were now able to be categorised as to their potential for successful treatment by these new drugs.

Brain tumour patients became aware of the first elements of personalised medicine in 2005 when those with a methylated MGMT promoter in their tumour sample had greater success with temozolomide (temodar) as part of the standard of care for GBM.

The reason I say that the methods are now generally different is that back in the early 2000s patients were subjected to specific tests related to the potential treatment. For example the MGMT test for brain tumour patients was not looking for other characteristics.

Today, samples of a person's tumour are subjected to a wide array of tests and its characteristics (expressions and deletions) are correlated with drugs that are known to be useful as anti-cancer agents against those genetic characteristics.

The problem is that even as these wide-array tests are increasingly being undertaken, they are expensive, and are not subsidised by the Federal Government.

I have heard of some brain tumour patients from Australia paying up to \$5,000 to have their tumour sample analysed in the USA to identify its potential for enrolment in clinical trials or to receive a targeted therapy thought to be relevant.

In addition to being a support organisation BTAA is an advocacy organisation and it would be perfectly proper for it to individually or collectively (perhaps with other patient advocacy organisations) campaign for Federal government subsidisation of these expensive tests.

The author, Denis Strangman AM, was Foundation Chair of Brain Tumour Australia, Foundation Secretary of Brain Tumour Alliance Australia, and the Foundation Chair (2005-2014) of the International Brain Tumour Alliance (IBTA). His late wife, Margaret, died from a GBM IV.

Sydney Support Network

The Sydney Brain Tumour Support Group meets each month at the Chris O'Brien Lifehouse in Camperdown. It is however, much more than a group of people living with a brain tumour, we are a family, fellow travellers who have become friends. Our mix is eclectic, in equal measure patient and carer.

High and low grade tumour patients and carers sit side by side knowing that we all have a new life in common, not a striving to necessarily go back to an old life but a determination to forge a new one. It keeps us all going, this encouragement we get from each other. We even, from time to time, hook up via video link to others who may not be able to get along in person, it's a work in progress to be sure but it's something we continually work on.

If our group has a culture it's inclusion - we welcome anyone, no matter where they are on the brain tumour journey, regardless of whether they are a patient, a carer, a family member or a friend because we recognise that

the patient is not the only one walking this road. If our culture is inclusion, our theme is hope, we never turn a blind eye to it, all of our meetings must have it at its core.

We aim also to make our meetings a place of safety, where each person can find a place to rest and equally, a place to be reassured that they are not alone, where someone arriving for the first time can be sure that they are in a safe place.

During 2018 we welcomed new members on an almost monthly basis. Sadly, during 2018 we also lost some of our dear friends but they remain with us. We welcomed some extraordinary guests, including Gail O'Brien herself, covering subjects such as brain cancer bio-banking, to leading edge research from Brainstorm at RPA that is encouraging us all that help is at hand in the form of research into this insidious disease, through to dietary insights to help us keep our bodies in the best shape we can.

We discussed thorny issues close to our hearts, such as fatigue and memory. We're also not afraid to try new things, delving into subjects

that at times might stretch us, but underpinned always by an understanding that most of all we want everyone to not only feel safe but to know that they do not travel this road alone.

We also provided, during the hectic year that was, that elusive commodity - space - where we kicked back a bit to take a breath and acknowledge each other's journey, each other's unique battles and each other's individual triumphs. It was a chance to just catch up with each other, checking in that things were okay. As Mozart once said "the beauty of music is not in the notes being played but in the space between them."

This is part of a mutual respect that permeates the whole group, an acknowledgement that all of us share the same essential experience but at the same time, gain new perspectives, new insights and new friendships. For Sydney-siders battling everything that living in the urban jungle throws at us, we find a place to slow down, rest, connect and dream.

Advocacy Campaign for Radiation Therapy for Regional Australia.

ASSOC. PROF. PETER O'BRIEN
CHAIR, RADIATION THERAPY FOR REGIONAL AUSTRALIA

In Australia only 1 in 3 cancer patients is receiving radiation therapy as part of their treatment plan, in contrast with 1 in 2 in Europe and North America.

The underuse of radiation therapy is a significant problem for regional cancer patients who cannot access a centre, but the problem is not simply distance but also a lack of information; radiation therapy is still under-recognised as the extremely precise, non-invasive treatment it is.

The Radiation Therapy Advisory Group (RTAG) is calling on the Federal Government and Opposition to promise to equalise access to radiation therapy for all Australians, through its new campaign Radiation Therapy for Regional Australia.

RTAG has identified 13 regional population centres that are especially disadvantaged by a lack of access to radiation therapy, and is asking politicians to provide funding and policy commitments to improve access in these areas.

What a lack of radiation therapy means for patients:

- Lower Survival rates
- Avoidable surgery
- Long Distance Travel
- Weeks away from home
- Lower survival

Each of these 13 population centres is more than an hour away from the nearest radiation therapy centre. Many are further away.

Studies show that people with cancer in regional areas are up to 35% more likely to die within 5 years of diagnosis than patients in the city. For many regional Australians, the distance is too far for regular trips. Many are not even told radiation therapy is an option for them. Those who receive radiation therapy have to face long drives and many nights away from home.



Hannah's Story

A story about complications is not going to be popular. So, if you're due for a craniotomy, I'd stop reading. But then again, maybe I'm a good news story? It all depends on how you see this.

In May 2017, I had a partial resection of a meningioma where one of the risks that they mentioned materialised. I had a brain bleed. A hemorrhage in my brain stem. This unfortunately, resulted in a brain stem stroke and "Locked In Syndrome". Luckily I have emerged from that and am now pretty functional with some mobility deficits and neural fatigue. I also have a slightly reduced vocal capacity and double vision, plus a very odd emotional experience of the world. A very heightened sense of the world. When I love, I LOVE. When I'm sad, I'm SAD. Don't tell me a sad story now, I'll be a blubbering heap in the corner. It's like every characteristic I had is on steroids. I was pretty empathetic, now I feel your pain so hard, I cry and think about it for months. Really feeling in the world is not all bad but having a 6th sense is intense, and tiring.

I would like to discuss the notion of risk and how it's conveyed before something like a craniotomy. Now, I'm highly educated, but not in the sciences. So, when they said 'stroke', I was like "yeah, I know that word, but that's like some minor medical condition right?" Don't assume people know. I was 35 years old and not really accustomed to stroke and the disabling effects of stroke. I'd never seen someone try and recover from one. I don't know if knowing any more would've actually changed my decision, I didn't really have any choice but I think the medical team needed to make it a little clearer how a risk may reverberate in someone's life. I'm thinking about this now because, despite it being almost two years on, I'm surprised at how the mental energy and focus required to keep on recovering seems even greater.

I do believe recovery is ongoing, but changing and forging new neural pathways is a lot of work. I got back to work, but am continually confronted with the fact that the path I was on is quite out of reach now, and this causes great sadness. Now I'm a blessing counter, don't get me wrong, but despite knowing how lucky we are, doesn't stop us from crying in a heap. 'Why couldn't my craniotomy be fine?'

Risks reverberate so heavily. It's not as simple as sitting in your office and telling someone they may struggle with balance afterwards. 'Struggle with' doesn't go on for years, maybe forever. 'Struggle with' does not mean can't sit up at all when you wake up. 'Struggle with' does not mean that almost two years on, you still have to plan every movement meticulously to avoid any incline with too much gradient. It reverberates into your supposed career, your marriage, your parenting, relationships with your family and friends...the list goes on. And it continues to reverberate for long after you've 'resected'.

Hannah Derwent had a partial resection of a meningioma in May 2017. It was complicated by a hemorrhage that gave her a stroke.



Hannah Derwent from the Canberra support group.



Hanna (centre) with members of the Canberra Support Group

2018 COGNO Latest Research

The 11th COGNO Annual Scientific Meeting was held on October 2019 in Brisbane. Led by Dr Mark Pinkham (Convenor) the theme was 'Targeting survival: living well with brain cancer in the era of precision treatments.'

We were very privileged to be joined by international guest speakers; Prof Mark Gilbert, Prof Eric Sulman, Prof Susan Chang and Dr Terri Armstrong, as well as many Australian experts.

Some topics/discussion at conference included:

- Reviewing challenges in testing Immunotherapies in Brain Tumor Clinical Trials: Mark Gilbert
- Developments in Radiation Therapy for Malignant Gliomas: Erik Sulman
- Patient-Centered Research in Neuro-Oncology: Improving Understanding of the Impact of CNS Tumours and Treatment: Terri Armstrong
- Update on current COGNO trials including CODEL: Liz Hovey; PersoMed-I: Liz Hovey; EX-TEM registry trial: Lucy Gately; and an International trial update by Craig Gedye: faith, hope and molecularity
- Survivorship and Supportive Therapies: looking at the benefits of using patient reported outcomes to improve patient symptom management led by Terri Armstrong and exercise to help improve cancer treatments led by Prue Cormie.

Congratulations to the award and grant recipients:

- MSD Hubert Stuerzl Memorial Educational Award 2018 - Dr Arian Lasocki
- COGNO Outreach Education Preceptorship - Dr Abdi Reza (Indonesia)
- COGNO Young Investigator Award - Mr Ali Dulfikar for his abstract 'Baseline functional status in post-operative glioma patients prior to adjuvant radiation: relevance to participation in a supervised exercise programme'
- COGNO Most Outstanding Oral Presentation - Dr Simon Puttick for his abstract 'Increasing antibody theranostic uptake in primary brain tumours using focussed ultrasound'
- COGNO Most Outstanding Poster Presentation - A/ Prof Zarnie Lwin for her abstract 'I'm the handbrake': a qualitative interview study of the experiences of informal carers for patients living with glioma"

- Inaugural BTAA Lynette Williams Award for best poster related to supportive care research:
 - » First prize - Ms Megan Jeon for her poster 'Prevalence and severity of difficulty sleeping in patients with CNS cancer receiving palliative care in Australia'
 - » Second prize - Miss Lobna Alukaidey for her poster 'Longitudinal health related quality of life in patients with benign and low-grade brain tumours'
- Inaugural #COGNO18 Top Tweeter Award - Dr Sarah Shigdar @SassStem

A huge thankyou to Brain Tumour Alliance Australia for bringing Terri Armstrong to Australia and along with William 'Billy' Williams, for initiating the BTAA Lynette Williams Award for best poster related to supportive care research Lucas Adda (Deputy Chair, COGNO Consumer Advisory Panel)

12th COGNO

ANNUAL SCIENTIFIC MEETING

SAVE THE DATE!

Sunday 27th - Tuesday 29th October 2019

SYDNEY, AUSTRALIA

For more information or to register for updates visit www.cogno.org.au



COGNO
COOPERATIVE TRIALS GROUP
FOR NEURO-ONCOLOGY



The BTAA team at COGNO

University of California San Francisco Releases New Care Giver Resources

Prominent USA Neuro-oncologist and researcher, Dr Susan Chang and her team at the UCSF Gordon Murray Caregiver Program have released a number of new guides for caregivers and families.

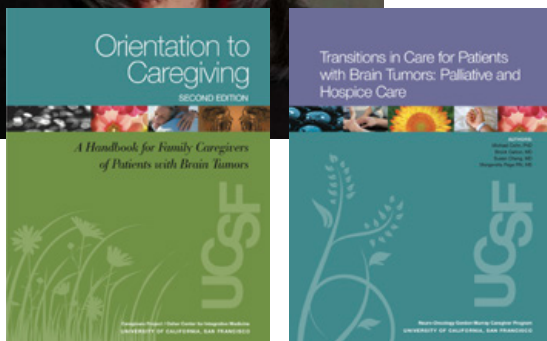
The UCSF Neuro-Oncology Gordon Murray Caregiver Program is named in honour of Gordon Murray, who was treated at UCSF for brain cancer and passed away in 2011. Grateful for the state-of-art care Mr. Murray received at UCSF, his wife Randi Murray led a fundraising campaign to build a program that helps families get the resources they need throughout the difficult experience of diagnosis, treatment, and bereavement.

Joined by philanthropists Cathy and Mike Podell, and Marritje and Jamie Greene, the Murray family raised over \$2 million to establish the UCSF Neuro-Oncology Gordon Murray Caregiver Program.

The three books available are:

- Orientation to Caregiving; A handbook for family caregivers of patients with brain tumours.
- Transitions in Care for Patients with Brain Tumours; Palliative and Hospice Care
- End of Life Care for Brain Tumour Patients

The Program has made these book available online free of charge to help brain tumour carers around the world. Links to PDFs of these books will be available soon on the BTAA website



Hunter Brain Cancer Forum



The 3rd Annual Hunter Brain Cancer Forum will be held this May.

When

Friday 10th May 2019 /10.00 am -2.00 pm

Where

West's New Lambton Bowling Club, Newcastle.

The day is free for attendees and is proudly supported by the Mark Hughes Foundation (MHF). Morning tea on arrival and lunch will be provided. The Forum is a day for patients, carers and their loved ones to hear specialists discuss a range of topics in relation to brain cancer.

Guest speakers include:

- Neuro Oncology Nurse Practitioner Marina Kastelan
- Neurosurgeon Dr Mitchell Hansen
- Medical Oncologist Dr James Lynam
- Social Worker Kate Jordison
- Clinical Psychologist Cathrine Adams

Stalls to provide further support materials will be held by CanTeen, NSW Cancer Council, Brain Tumour Alliance Australia (BTAA) and the Hunter Cancer Biobank.

In addition to gaining further information and resources, we hope the Forum helps attendees to build connections with other patients and carers going through the same journey, to help them realise they are not alone in this fight.

If you would like to attend, please register your attendance by calling Sharyn at the MHF office; Ph. 4037 7400 or email enquiries@markhughesfoundation.com.au please include how many people will be attending and any dietary requirements.

Please arrive between 9:30am and 9:50am for registration and morning tea. Lunch will be provided at 12pm and the day will come to a close by 2:30pm. If you require accommodation, West's New Lambton have wonderful facilities (phone: 02 4935 1200, website: www.westsnewcastle.com.au).

We welcome everyone with open arms and look forward to seeing you there.

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★ **DATE SAVER** ★

MEL'S GO GREY IN MAY 2019

SATURDAY 25TH MAY

BATHURST PANTHERS



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
various videos

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