



THE OFFICIAL BTAA NEWSLETTER

# International Brain Tumour Awareness Week Edition

22- 29 OCTOBER 2016

[BTAA.ORG.AU](http://BTAA.ORG.AU)

This newsletter was produced with the assistance of donors to Thomas Daldy's Ride in memory of Pedro Café.

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## Cancer Australia's Consumer Forum

*Tricia Berman, Susan Pitt, Keri Huxley, Owen Finegan, Helen Zorbas, Annabelle Wilson @ Cancer Australia Consumer Forum (Image courtesy of Cancer Australia)*



## Mel's Goes Grey in May

*Melissa Johnson, A/P Michael Buckland, Dr Kim Kaufman and Baby Vivienne, at Lifeshouse at RPA.*



Brain Tumour Alliance Australia



@BrainTumourAA



Search 'BTAA' for various videos

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Freecall number 1800 857 221



# SUPPORT IS AVAILABLE

**BTAA Freecall 1800 857 221.**  
Email [btaa@shout.org.au](mailto:btaa@shout.org.au)

Peer to peer support around Australia listed on [www.btaa.org.au/page/26/support-organisations](http://www.btaa.org.au/page/26/support-organisations)

Cancer Connect telephone (13 11 20)

Brain Tumour Patients Telephone Support Group  
Freecall 1300 755 632

Monday - Friday 9am - 5pm  
or email [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au)

Cancer Connections (online)  
[www.cancerconnections.com.au](http://www.cancerconnections.com.au)

Centre for Community-Driven Research Support clinic  
via telephone. To access this service call 1300 42 68 77  
or email [nurse@cc-dr.org](mailto:nurse@cc-dr.org). [www.13004anurse.org](http://www.13004anurse.org)

## DIARY DATES

### SEPTEMBER 2016

#### ASNO/COGNO ASM,

11-14 September, Sydney  
[asnocogno2016.org.au](http://asnocogno2016.org.au)

#### Free Educational Forum,

Sydney, 13 September  
[www.btaa.org.au/events](http://www.btaa.org.au/events)

#### BTAA AGM and 4th National Summit,

14 September, by invitation

#### Health Professionals Educational Forum,

The Canberra Hospital, 15 September

#### Curefest Australia,

25 September.  
[www.curefest.org.au](http://www.curefest.org.au)

### OCTOBER 2016

#### International Brain Tumour Awareness Week,

22- 29 October 2016

#### IBTA Week Lunch

Wed 26 Oct between 1pm and 3pm  
in the SolarisCare Community Garden at  
Sir Charles Gairdner Hospital.

### NOVEMBER 2016

#### Society of Neuro-Oncology ASM (SNO)

17-20 November, Phoenix, Arizona, USA

See a list of international conferences for 2017  
here [theibta.org/events-and-conferences/](http://theibta.org/events-and-conferences/)

See our **Nicola Scott** [educational grants](#) for nurses,  
allied health and researchers.

**CABARET FOR COGNO**

MONDAY 12 SEPTEMBER 8.00 - 10.30 PM  
SHERATON ON THE PARK

A night of fantastically fabulous fun  
supporting Australian brain tumour research

FEATURING STARS OF STAGE AND SCREEN

MC: Christa Hughes Musical Director: Luke Byrne  
Genevieve Lemon Vashti Hughes Katie-Elle Reeve  
Joanna Weinberg Brendan Hay Alexis Fishman  
Lisa Hanssens Leonie Cohen Christopher Tomkinson

AND MORE!

Tickets \$80 available from  
<https://arinex.eventsair.com/asno-2016/form7>



# LETTER FROM THE CHAIR

## Hello all

On behalf of BTAA I extend a very special welcome to all those attending the 13th Asian Society for Neuro-Oncology and the 9th Cooperative Trials Group for Neuro-Oncology Annual Scientific meeting in Sydney from 11 to 14 September 2016. Known as the ASNO/COGNO ASM for short!

If you are coming to the ASNO/COGNO ASM please come and say hello to Sally and Chris from The IBTA who will be sharing a stall with BTAA at the Sheraton on the Park, Sydney. Read more about this meeting here <http://asnocogno2016.org.au/>

## Come and Meet Mary Lovely

BTAA is sponsoring **Associate Adjunct Professor Mary Lovely's** trip to Australia and New Zealand in September. It's a long flight from Mary's home in San Francisco. Thanks Mary for taking the time to join us. Mary will participate in the **free educational forum** on the morning of **13 September**, and lead some sessions in the afternoon at the ASNO/COGNO ASM. The next day she will share her experience with those attending the BTAA Summit on the 14<sup>th</sup> of September, and then head to Canberra that afternoon. On the 15<sup>th</sup> of September Mary will deliver a session at The Canberra Hospital for health professionals, organised by **Juliane Samara** - Gynaecology, Brain and CNS Specialist Nurse.

Mary will fly to New Zealand on the 17<sup>th</sup> of September to talk to several groups there organised by **Chris Tse** of the IBTA. Then it is back to Sydney to fly home. Thanks Mary very much for sharing your experience with us.

**Free Forum – 13 September 2016, Sheraton on the Park, Sydney, 10am – 12 noon**

Hear the International Speakers including **Mary Lovely, Mitchel Berger** and **Paul Mischel** at a **free educational forum** for nurses, allied health professionals and patient/carers hosted by the NSW Oncology Group – Neuro Oncology, in association with the ASNO/COGNO ASM.

You can do just the core two hours, from 10am to Noon, or stay on for a free lunch session and even stay longer if you want to hear more on supportive care. See the full program and register here <http://www.btaa.org.au/events>

## Curefest Australia

There is a very important gathering on **25 September** in Sydney. The second **Curefest Australia for Childhood Cancer** will be held at the Sydney Opera House Northern Broadwalk. There will be a candlelight vigil the night before, **24 September**, in the Opera House forecourt. You can volunteer to help – see <http://www.curefest.org.au/volunteer>

## IBTA Week 2016

An important initiative of the IBTA is **International Brain Tumour Awareness Week**, which runs from **22 – 29 October in 2016**. Plan a lunch or a walk or a display - Read more about our alliance partners important work in the article from **Chris Tse** in this issue. See how you can raise awareness and participate in the **Walk Around the World for Brain Tumours** at <http://theibta.org/awareness-raising/#one>

**Perth** will mark the week with a lunch on Wed 26 Oct between 1pm and 3pm in the SolarisCare Community Garden at Sir Charles Gairdner Hospital organised by **Diana Andrew**.

## Educational Grants

BTAA has educational grants available to help nurses, allied health professionals and researchers with a particular interest in brain tumours attend national and international events.

Read more about these grants, offered with the assistance of the **Nicola Scott Educational Trust**, here <http://www.btaa.org.au/news/77/btaa-educational-grants->

## Photos

- In this issue we have some photos of our Goodwill Ambassador **Mel Johnson**, and her supporters at her third **Mel Goes Grey in May for BTAA and Brainstorm at RPA**.
- Thanks also to **Engineers Australia ACT Office**, for a great Christmas in July Trivia night.
- Also see some images from the first meeting of the BTAA Steering Committee for our **Cancer Australia** grant held in Melbourne. Read more about the grant in this issue. Thank you to those working with BTAA on this important project.
- Also some photos taken at the **Cancer Australia Consumer Forum**. Great to see our community well represented.
- Also some photos from the **BTAA Planning Day** so you can put a face to your BTAA.

## BTAA AGM and Summit

The BTAA Annual General Meeting will be held on **14 September 2016** in association with the

**4th BTAA Summit**. Secretary Tricia Berman has mailed the meeting papers to our financial members, who are also invited to join us at the Summit. I encourage you to

consider becoming a financial member of BTAA – **there are less than 100 of you**, while there are more than **1,800** subscribers to information services. <http://www.btaa.org.au/page/23/become-a-member>

## Bouquets and thanks

Thanks **Susan Dalliston**, for walking the Larapinta Trail to raise money for the **Cure Brain Cancer Foundation** and awareness.

Thanks **Philip Steel** who has led us in developing a more robust structure this year. At the 4th BTAA Summit Philip will outline the next steps. We need our alliance partners' help to grow our voice and we have some important work to do setting up our new teams.

- **SUPPORT** – supporting all brain tumour patients and carers and their families
- **COMMUNICATION** – communicating the messages of BTAA to patients and carers
- **CONNECTION** – connecting to like-minded groups
- **REPRESENTATION** – advocating and representing the BTAA community

We are also looking for help with a new peer support service to operate out of the **Chris O'Brien Lifehouse**. **Catherine Hindson**, of the BTAA Support Team, will be working to get this service operating, with our first meeting at the **Chris O'Brien Lifehouse** on 18 August. Email [support@btaa.org.au](mailto:support@btaa.org.au) for more information.

Catherine is also working with The Canberra Hospital to provide a new peer support service at The Canberra Hospital.

Thanks to Tasmanian Senator **Catryna Bilyk** who convenes the Parliamentary Brain Tumour Awareness Group.

Finally thanks Catherine, and the rest of the BTAA Committee, **Tricia, Philip, Mary Anne, Janet, Rigoula and Julia**. Also to **Mark, Diana, Nicola, Denis, Anita, Bob and Matt**. Matt was the original Chair of BTAA, and he claims, the best.

See more about our people here <http://www.btaa.org.au/page/10/our-people>

**Susan Pitt**

Chair, BTAA

# Cancer Australia's Consumer Forum



Consumers in the room - Cancer Australia Consumer Forum. (Image provided by Cancer Australia)

By Susan Pitt

**BTAA was represented at the Cancer Australia Consumer Forum on Monday 27 June 2016 by Chair Susan Pitt and Secretary Tricia Berman.**

It was an opportunity to network with other Cancer groups as well as catching up with those with a particular interest in brain tumours.

It was great to catch up with others with a particular interest in brain tumours including **Keri Huxley, Annabelle Wilson** and **Owen Finegan**.





*BTAA Steering and Project Committee Meeting, Melbourne.*

## Cancer Australia Grant Progress

*By Tricia Berman, BTAA Grant Coordinator*

**In April 2016, the BTAA received funding from Cancer Australia for a three-year project to 'create information resources to help brain tumour patients improve the health and quality of life outcomes for people from culturally linguistically and diverse communities, including Arabic, Greek, Chinese, Vietnamese and Easy English'. (In the second year we will look at five more languages.)**

The first meeting of the Steering Committee on 2 August in Melbourne identified a pathway forward for the BTAA project. The Chair of the Chinese Cancer Society of Victoria and a representative of Breast Cancer Australia Network contributed to the meeting. The meeting decided to hold four Focus Group meetings – two with patients and two with allied health professionals – over the next two months to obtain feedback on resources to assist brain tumour patients in CALD communities to understand what is available for support and how to get assistance immediately after diagnosis.

The initial four Focus Groups will be held in Melbourne, Sydney and Brisbane.

The 4th National BTAA Summit (14 September 2016) will include a session on the progress of the CA project.

Read more about the project here.

<https://www.btaa.org.au/news/82/btaa-cancer-australia-project->



*Danette, Sally and Jonathon checking their devices, lunch break, Cancer Australia BTAA grant steering committee meeting.*

## Updated Gliolan Fact Sheet

*By Susan Pitt*

**Gliolan® (aminolevulinic acid HCl), also known as ALA, is a drug that helps neurosurgeons work out what is tumour and what is health tissue during surgery. The drug causes malignant brain tumours to fluoresce when a specialised blue light is used to resect the malignant tissue. Gliolan causes tumours to glow pink whilst healthy brain tissue appears blue. This has the effect of highlighting the tumour and enables the surgeon to more clearly see, and better resect the tumour. This method is known as fluorescence guided surgery, and is used to resect both primary tumours and recurrent GBM.**

Gliolan is not yet reimbursed by the Federal Government, however the Melbourne based company who distributes the drug, Specialised Therapeutics Australia, have made a submission for reimbursement and the outcome should be known towards the middle of 2017.

Fluorescence guided surgery with Gliolan is available at 27 public and private hospitals across Australia, however patients will need to self-fund the drug in private hospitals, or ask their private insurer if they can assist with the cost. It is also available in several New Zealand hospitals.

Whilst a number of public hospitals have the capability to operate using Gliolan-induced fluorescence, not all of them fund this method, so patients will need to check if Gliolan is available at the public hospital where they are being treated. The cost of Gliolan is \$3,990 per vial.

**Read the list of hospitals that have the capability to use this drug, and more about using ALA, here on the About Brain Tumours page of our web site <https://www.btaa.org.au/page/27/gliolan-faq>**

# International Brain Tumour Awareness Week | 22-29 October 2016

By Chris Tse International Brain Tumour Alliance (IBTA)

The International Brain Tumour Awareness Week (#IBTAWeek) is one of two major awareness raising campaigns run annually by the IBTA, the other being the Walk Around The World For Brain Tumours.

The International Brain Tumour Awareness Week provides an opportunity for people from around the world to organise or participate in an awareness raising activity for brain tumours, from large scale events such as a conference or fund raising gala to smaller activities such as a tea party, dinner, or support meeting for patients and caregivers.

Leading up to the Week, brain tumour patient organisations are encouraged to issue press releases to their local media contacts, submit articles to the newspaper, or arrange radio or TV interviews. We are also planning a social media campaign on Twitter and Facebook using the hashtag #IBTAWeek.

This is the tenth year that the International Brain Tumour Awareness Week is being held and each year we are amazed by the creative ideas that people come up with. For example, last year the Singapore Brain Tumour Society organised a super car rally down the famous Orchard Road, which achieved widespread news coverage across Asia. We can't wait to find out what events will be held, and from which countries, for the 2016 Week.

The IBTA has supporting organisations in all corners of the world and this year the 2016 edition of our "Brain Tumour" magazine was sent out to recipients in 113 countries. An important part of our work is to encourage the establishment of brain tumour patient and caregiver support groups in countries where they don't currently exist, and in the past year we were delighted to help in the formation of a new organisation in Cameroon, Africa.

In Australia, the IBTA has close associations with **Brain Tumour Alliance Australia (BTAA)** and **Cure Brain Cancer Foundation**, among others.

On 11-14 September the IBTA is excited to be partnering with BTAA to exhibit at the ASNO-COGNO joint annual meeting in Sydney. The IBTA will be represented at the meeting by Sally Payne (Australia) and Chris Tse (NZ). If you are coming to the conference, make sure to drop by the BTAA/IBTA booth and say hello. We would love to meet you!

**Chris Tse**



Chris Tse at the IBTA Summit, Sitges 2015



Stuart Farrimond and Sally Payne, IBTA Summit, Sitges, 2015

Images courtesy of Susan Pitt





BTAA Planning Day – Rigoula, Julia, Mark, Philip, Janet, Tricia, Susan and Catherine

BTAA at work.

## Janet Represents Australia in Toronto

By Janet Micallef, Committee Member

**The 1st Worldwide Meningioma Conference in Toronto was an amazing two days, attended by 140 Neurosurgeons worldwide. The format was eight hours of lecture style presentations from Neurosurgeons and Scientists.**

By way of background, the reason for this first world-wide conference on meningioma is due to the fact that both USA and Canada have increased the use of MRI on patients and, as a consequence of having increased screening the incidence of Meningioma has substantially increased.

The topics for discussion were under the following categories:-

- Tumour Biology: Animal biology and cell Biology
- Radiology response and RANO in Meningioma
- Clinical studies - Guiding future care for Meningioma
- Surgical perspectives for Meningioma
- Special Advocacy session and Poster session and reception
- Genomics and Molecular Advances in Meningioma
- Lessons from our clinical Experience in Meningioma
- Update on International Clinical Trials in Meningioma
- Radiation Therapy and Radiosurgery Practices for Meningioma

Over the two days each presentation was followed with question time, 3 panel discussions and a poster session on their abstracts.

There was a special advocacy session - Patient Advocacy and Funding Mechanisms with a patient perspective on issues patients have including the issue of fatigue. Brain Tumour Foundation of America presented its findings from insights from patients and caregivers about their brain tumor experiences from diagnosis and throughout their journey of a Brain tumour. The ABTA's first survey in 2015 elicited responses from more than 2,300 patients and caregivers representing all tumor types. see more information on this survey -

[http://www.abta.org/about-us/news/press-releases/PFC2016\\_MeningiomaSurvey.html](http://www.abta.org/about-us/news/press-releases/PFC2016_MeningiomaSurvey.html)

It was interesting to learn that the 2016 revision of the World Health organisation (WHO) classification of Central Nervous Systems (CNS) Tumours made a major notable change in the addition of 'brain invasion' as a criterion for atypical meningioma. For full details see link <https://www.thebraintumourcharity.org/media-centre/news/latest-news/who-updated-classification-tumours/>

Interestingly immunotherapy trials on canine Meningioma using big dogs in particular Golden Retrievers and German Shepherds.

Presenting - Most grade 2&3 locations in olfactory and frontal lobe.

Grooming Meningiomas in lab cells to get clinical trials with vaccines for dogs and people.

The program on the dogs was interesting, and it was noted that they have a similar lifestyle and tends to mirror the activities of the human owner i.e. eats, exercises, sleeps at the same time as its owner.

The conference ended on a high note with the last speaker talking about health related quality of life in meningioma patients. Little is known about the health related quality of life of patients with meningiomas. Their objective is to investigate the long term effects in patients with meningioma and its association with cognitive deficits and epilepsy/seizures.

It was a pleasure to represent Australia and BTAA at the conference. It was great to see so many learned people with a one common goal and that their enthusiasm to this was a real delight to see. It was agreed that another conference would be held in the not too distant future.

*Thanks Janet Micallef who flew all the way to Toronto to represent BTAA at the 1st Worldwide conference on Meningioma on June 17 and 18 at Toronto. BTAA was keen to have a representative at this Society of Neuro-Oncology (SNO) conference. Janet is a Melbourne based patient and co-founder of Grey Matters Brain Tumour Support Group.*

*Janet was diagnosed with a meningioma in 1984. Her last operation was in 2014.*

# Communicating with others after a brain tumour diagnosis

By Lee Cubis

A diagnosis of brain tumour, whether benign or malignant, can leave a substantial impact on your relationships with others. Changes to physical abilities, headaches and seizures, difficulties with speech, memory and organisation, driving restrictions and emotional responses to brain tumour can make connecting and communicating with others difficult. Naturally, friends and family are likely to be curious about what's going on; however keeping everybody informed can be exhausting, especially when you are dealing with the ongoing effects brain tumour. Communicating effectively with your social groups (i.e. friends, extended family, work colleagues etc) enhances your ability to receive support from others.

Conversely, you may be feeling overwhelmed with support and need some space. There is no right and wrong when it comes to communicating with others about your brain tumour, however it is beneficial to take some time to decide who you wish to tell what and when. You may decide to tell your very close friends and family everything, however filter what you share with your wider social networks. Other people opt to share their entire story with everybody in their network, and that is also fine.

Things you may (or may not) wish to communicate to others:

- Initial diagnosis
- Treatment regime and outcomes
- Recurrence
- Impact of brain tumour and treatments (e.g. physical, communication, emotional)
- What you need (or don't need) from others
- Prognosis

Tips for sharing information with different groups:

## Close friends and family

Close friends and family may attend appointments with you and therefore receive updates at the same time as you. Some people decide to have "family meetings" to let everybody know what is happening, and what they can do to be of assistance. It can be helpful to make a list of points that you wish to cover in these meetings as they can become somewhat emotional and tangential. If there are a lot of people to share information with, delegating a family member to make the phone calls or send text message updates can assist you in preserving physical and emotional energy.

## Wider social network (e.g. work colleagues, extended family)

When living with the effects of brain tumour, it is completely fine to communicate news and updates via telephone, email, text messages and social media (e.g. Facebook). Short texts or status updates such as "3 weeks of radiation down, 3 to go!"; "Thanks for all the support, my MRI was clear again!"; "Not so good news today, Christine needs another round of chemo."; or "Thanks everyone for your supportive messages, sorry we haven't been able to get back to everyone just yet – we are all very exhausted" are an efficient way to give updates without having to repeat yourself many times. Longer updates or emails can effectively update your wider social network and may include the following:

- Latest update
- How everyone is going
- What people can do to help (including giving you space, or meeting you for coffee)
- What is coming up next for you
- The best way to make contact (e.g. by text, telephone, social media)

An example of what this may look like is "Hi everybody, I just wanted to give you all an update on how I am going with my treatment. I'm sorry I haven't been able to answer all of your messages. Treatment is going well, I have done 5 of my 6 rounds of chemo and have an MRI booked for next week. I am very tired at the moment, but will be ready for coffee dates in the coming weeks. I'm finding it hard to read text messages at the moment, but Tony is helping me out with that. Feel free to message me anytime, but it may take me a while to respond".





### Strategies for family and friends to support somebody with brain tumour

- Take the time to understand what the person is experiencing with ongoing symptoms and emotional wellbeing.
- Encourage open communication around what is helpful and what is not. Some people want to talk through their brain tumour experience; others want to spend time getting back to “normal” activities.
- Give the person space to discuss their challenges, fears and emotions if they wish.
- Support the person to maintain their sense of normality by continuing with regular activities.
- If physical, cognitive or logistic issues make this difficult; brainstorm a new way to do things (e.g. meet for coffee if the person is not up for squash at the moment; assist with transport if they are unable to drive).

### Getting support

Getting support is integral to managing distress related to your brain tumour. A Psychologist or Counsellor can also help you with strategies for managing communication with others or social

effects of brain tumour. The Cancer Council Counselling Service offers free and confidential

telephone and face-to- face counselling to help people with brain tumour and those close to them. People can be referred to the service or find out about support and referrals to specific agencies by calling Cancer Council Helpline on 13 11 20.

### Staying Connected after Brain Tumour research

Griffith University in collaboration with Cancer Council Queensland is researching the effects of brain tumour on social and psychological wellbeing, as well as the ways that people with brain tumour stay connected to others. The Staying Connected after Brain Tumour research has been granted ethical approval through the Griffith University HREC. Participation involves a 45 minute interview either over the telephone or in person (if you reside within 2 hours of Brisbane).

**If you would like to know more about the Staying Connected after Brain Tumour research, or would like to take part, please contact Lee Cubis on [lee.cubis@griffithuni.edu.au](mailto:lee.cubis@griffithuni.edu.au) or 0438 208 783.**

# Mark Hughes Foundation News

**The Mark Hughes Foundation (MHF) is funding the Hunter New England region’s first ever Care Coordination Nurse for people with brain cancer, serving as a vital intermediary between health staff, patients and medical researchers.**

Under the three-year arrangement, neurosurgical nurse Jane Morison has been providing support to people receiving care at the John Hunter and Calvary Mater Newcastle hospitals.

A full-time applicant, Sandy Nixon, has just been recruited.

It’s part of a pilot research project aimed at addressing the needs of brain cancer patients during and after treatments and linking them with current research projects and clinical trials.

The long-term vision is to prove the validity of this position across local health districts.

Nurse Nixon will help explain medical information provided by surgeons, oncologists, radiologists and Allied Health staff to help patients work through their options. She will collect research data and also encourage use of brain cancer biobanking that MHF also supports.

Data and outcomes are forwarded to the MHF Scientific Committee for evaluation.

Mark and wife Kirralee Hughes started the Foundation to boost medical research into brain

cancer but also realised there was a need to assist patients at the start of their cancerJourney.

“I go back to when Kirralee and I were hit with the bombshell that I had brain cancer. You want answers, you want support,” Mark Hughes said. “We were getting snippets of information from our doctors but felt there needed to be someone who could glue it together for families.”

Jane Morison met Mark Hughes the day he was admitted to her ward



*Caption: Jane Morison with Mark Hughes (Image: Provided by the MHF)*

for an operation to remove a brain tumour and was excited to finally work for his fundraising group: “A gap sometimes exists between the time of diagnosis and the person going home to await the next step, however we’ve never had someone delegated to purely look after people with brain cancer. The Foundation has made it possible,” she said.

Both the Brain Cancer Care Coordinator and Biobank representative hand out MHF Packs to patients. These include a calendar, MHF beanie, pen and a handy magnet to place on the fridge with contact details for the Brain Cancer Care Coordinator for those times when advise or support is required.

MHF have received fantastic and heart-warming praise of Jane and the Brain Cancer Care Coordinator role. Mark Hughes personally called upon Jane’s services recently after suffering a recurrence of acute headaches.

“Luckily I was OK but Jane was wonderful throughout,” Mark said. “As that special someone here looking out for patients and 100 per cent focused on brain cancer care and research,the coordination role a fantastic asset to the community,” Mark added.

## Cancer Voices Calls for Equity

*By Susan Pitt*

**Wouldn’t it be great if all brain tumour patients, in fact all cancer patients, could have access to a care coordinator like Jane Morison?**

Sally Crossing AM, Convenor of Cancer Voices Australia, has written to the Commonwealth Minister for Health, Sussan Ley, regarding equity of access to specialist cancer nurses. Sally wrote that this is a long standing issue and some cancers have succeeded in attracting Commonwealth funding to support their access programs.

Cancer Voices has called on the Minister to see all cancer patients, as far as practicable, to be able to benefit from wonderful, system-efficient care and guidance.

BTAA supports Sally’s call for real equity of access to cancer nurses for all.

As Sally says “It would be great news to Australians coping with treatment associated with our biggest disease burden – cancer.”

**See more about Cancer Voices at [www.cancervoices.org.au](http://www.cancervoices.org.au) and [www.cancervoicesaustralia.org](http://www.cancervoicesaustralia.org)**





Tom (18 months post op), Tina (12 months post op), Michelle (3 years post op), Lisa (6 years post op), Stacey (10 years post op) and Julia Robertson (5 years post op)

## Julia's Fabulous Adventure

By Julia Robertson

About eight years ago I found a group of people on Facebook who had the same brain tumour as mine, a Colloid Cyst of the third ventricle. These are very rare benign brain tumours. At that time there were around 200 of us from around the world in the group and we offered each other a lot of moral support through each of our individual journeys. If I had not discovered the group, made some amazing new friends there and been given so much support and encouragement by then, I would not have had the confidence to go and have another opinion about surgical options and would not have survived to this point.

Over the mid-year break from University, my husband and I travelled to America and met up with some of the members of what I call my 'brain family.' Six of us were able to catch up together in Las Vegas for the day. They had travelled from various different places in the USA and most had not met each other in person before. It was the 10 year 'brainiversary' for Stacey, she spoke to me online the night before I went in for my surgery in 2011. Tina has just celebrated her first 'brainiversary'. It was a fantastic experience to be able to finally meet some of the people I have had such a close relationship with on line.

Being able to share our stories and outcomes was an incredible opportunity to see how far we have each come in our recovery but also gave us amazing insight into the improvements and advances in Brain surgery techniques. The 'babies' of the day, 12 and 18 months post op, have both had very few if any memory issues and were back at work in no time. There are plans to do it again next year but in London instead of Las Vegas.

Support networks are important for everyone. I found my social networks shrank and even broke down while I was ill so the support I found on-line was even more precious to me. The group is not far from 2000 members now.

## Research on Living with a Low-Grade Glioma

BTAA encourages you to consider participating in this research if you are an adult living with a low-grade glioma.

Dianne Legge from the Institute of Health & Biomedical Innovation at Queensland University of Technology, is doing a study as part of a Masters of Applied Science (Research) into how people adapt to living with a low-grade glioma.

Dianne is interested in talking to males and females over the age of 18, who have been diagnosed with a low-grade glioma more than 3 months ago (and not more than 10 years ago).

Participants will be asked to take part in a 60-90 minute interview at the Olivia Newton-John Cancer Wellness & Research Centre, Melbourne. (Telephone interviews may be an option).

What is it like to be diagnosed with a low-grade glioma? How do you adapt to this change in your life? Or how do you make sense of your experience?

This study aims to understand the ways people with a low-grade glioma adapt to their illness, what resources they use and how they cope.... Participants will be asked to take part in a 60-90 minute interview with research interviewer, Dianne Legge at the Olivia Newton-John Cancer & Wellness Centre, Melbourne. To register your interest or learn more, please contact Dianne Legge on 03 9496 3315 or [dianne.legge@hdr.qut.edu.au](mailto:dianne.legge@hdr.qut.edu.au).

This study is being undertaken by Dianne Legge as part of a Masters of Applied Science (Research) at Queensland University of Technology, and has been approved by Austin Health Human Research Ethics Committee Reference Number HREC/16/Austin/184.

Please note that the "Living Now with LGG" study has been approved by the Austin Health Human Research Ethics Committee HREC/16/Austin/184.

(Phone interviews may be possible if you cannot get to Melbourne.)

### Contacts

**Dianne Legge**  
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## Brain Cancer Biobanking Australia (BCBA) launches Australia's first national register of brain cancer biospecimens

By Robyn Leonard

**For first time in Australia brain cancer researchers are able to access a national online register and locate tissue samples to build their projects.**

The collaborative effort of the BCBA consortium of leading paediatric and adult clinicians, researchers and biobankers was rewarded recently with the launch of the centralised register of brain cancer biospecimens collected and stored in the BCBA network of 17 biobanks across Australia.

With the ongoing support of this collegiate brain cancer community BCBA will continue to expedite access and sharing of brain tumour biospecimens and develop as a national platform to resource Australia for brain cancer research.

BCBA is supported by **Roche Australia, Cancer Council NSW, Robert Connor Dawes Foundation, Isabella and Marcus Paediatric Brainstem Tumour Fund** and **DDB Remedy**.



## Mark's Meditation

By Mark Dalliston

### Introduction

**I found that once I discovered what meditation was, it is easy to practice. I have tried it in classes. I failed to understand what I was meant to be doing.**

Fast forward to two months ago. I was in bed, and the realisation hit me that I was meditating. I began my practice daily.

Whatever way works for you follows. It can be as simple as downloading the Smiling Minds app on your smartphone.

### What meditation is not?

Not a higher form of consciousness or attempt to reach nirvana. Nor spending ten years as a hermit in a cave. You don't have to spend hours daily.

### What is meditation?

One description I like is a time out from thinking. This time out leads to lack of stress and anxiety.

There follows an absence of fear and promotion of peace. All benefits flow from as little as 20 mins per day.

Thousands of research studies support the advantages. These papers may not validate joy, but many of them will verify calmness.

### Conclusion

I was a sceptic until meditation worked for me. When you have cancer taking time out from thinking can prevent anxiety and fear of the future. Awareness of the present helps. I contend anyone can enjoy the benefits, once they understand such reflection is mastering listening, usually to a voice.

**Mark Dalliston is co-editor of the BTAA e-news and newsletter.**



# Education and support study for carers of people with high grade glioma opens in NSW and WA

By *AI/Professor Georgia Halkett*

**Carers play an essential role in looking after people diagnosed with high grade gliomas. Our research team has previously found that many carers are very distressed and do not feel well prepared for their caring role. Cancer Australia has funded this randomised clinical trial which will study whether a nurse-led education and support program can help carers prepare for caring, improve their quality of life, reduce distress, anxiety and depression; and decrease unplanned use of health services.**

The carer education and support program includes a telephone assessment of the carer's needs, a nurse home visit, a personalised printed resource file tailored to the specific needs of that carer and patient, and ongoing telephone support for 12 months. Some examples of carers needs include encouraging them to care for themselves (mental and physical health); help communicating with doctors; help understanding treatment; information on understanding physical symptoms; understanding mental and behaviour changes; making choices on fertility and sexuality; lifestyle choices such as diet, exercise and complementary medicines, and end of life care. When the nurse identifies these unmet needs, he or she can give extra information, support, education and refer to someone else who can help in more depth, if needed. Because things can change quickly when caring for someone with high grade glioma, the nurse calls each month to check in on new concerns and is also available for ongoing phone support.

Although it seems obvious that extra support will help carers, to persuade Medicare and health services to include this type of program as routine, we need to also prove that it helps. The only way to do this is to compare two groups of similar carers, who do or do not receive the extra support. To understand whether the carer support program truly makes a difference to carers, half the carers who participate in the study are randomly assigned to have contact with the 'carer nurse' and receive the extra support and education package, and the other half will continue to receive the usual support and education which is available through the patient's treatment centre. Both groups of carers fill in questionnaires so that we can understand and compare their quality of life and emotional health. Healthcare systems will also want to understand whether extra support in the short term reduces



healthcare costs in the long term – for example, by reducing hospital admissions through supporting carers better. This study is also looking in detail at the economic costs and savings of the support package, which is why we are asking people in the study to keep track of healthcare costs, hospital visits, and allied health visits.

To date, 82 carers from WA have joined the study and are helping to answer this important question. The study will start in NSW later this year, and we will be able to include people in many areas of metropolitan Sydney. This study is being presented as a poster at the COGNO conference. We welcome enquiries about the study via email: [g.halkett@curtin.edu.au](mailto:g.halkett@curtin.edu.au).

**Associate Professor Georgia Halkett**  
**PhD, FIR, BMedRad(Hons), Radiation Therapist**

**Senior Research Fellow, School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences**

**SAVE THE DATE**  
**Men's Retreat for Brain Cancer**  
 hosted by *Peace of Mind Foundation*

*Saturday and Sunday  
 8th - 9th  
 October 2016*

Anglesea Beachfront Caravan Park  
 Anglesea, Victoria

Tickets can be purchased online at [www.peaceofmindfoundation.org.au](http://www.peaceofmindfoundation.org.au)

For more info please contact Bec Picone (Director) on 0411 382 457 or [bec@peaceofmindfoundation.org.au](mailto:bec@peaceofmindfoundation.org.au)

An exclusive men's weekend of action packed fun for male brain tumour patients, carers and mates!

Overnight Camp Out - Beer Tasting - Brewery Tour - Golf - Laser Strike - Fishing - Canoeing - Aussie BBQ - Inspiring Guest Speakers - Chance to make some great mates!

\$140 per person (all inclusive - camp accommodation)  
 Be quick to book - Limited to 80 places only!

\*Cabin accommodation available upon request at an additional rate\*

# Men's Retreat for Brain Cancer

By Bec Picone

Peace of Mind Foundation will be hosting the Men's Retreat for Brain Cancer on October 8-9th in Anglesea, Victoria. This is an exclusive blokes weekend of jam packed fun and an opportunity to connect with other men who are also travelling the brain tumour journey. Any men who have been personally affected by a brain tumour diagnosis (patient, carer, friend or family member) are welcome to come along! Fathers are also more than welcome to bring their teenage sons (12 years and over) or guys can feel free to bring a mate for company.

Peace of Mind is offering a free pick up and drop off transport service for all guests coming from interstate or outside the Geelong/Surfcoast region. We will collect you from Melbourne/Avalon Airport or Flinders St Station and take you to the retreat!

Full itineraries will be emailed out to attendees later in August but here is a quick run of events for the weekend:

We start off with a beer tasting workshop and pub lunch at Little Creatures Brewery in Geelong. Men will then go off to their chosen afternoon elective; either 9 holes golf at Anglesea Golf Course, Laser Strike in Geelong, or a

4WD/pillion motorbike adventure down Great Ocean Road!!! We will be camping out at the fabulous Anglesea Beachfront Holiday Park and enjoy a yummy Aussie BBQ dinner on the Saturday evening. Following this the men will have the opportunity to hear some inspiring stories from our fabulous guest speakers that we have lined up for the night. On the Sunday the men will have plenty of down time and opportunity to go kayaking/ paddle boating up the Anglesea river, fishing, sports, pedal carts, swimming, spa and even remote control car races! The retreat will conclude after lunch on the Sunday approximately 3pm.

\$140 per ticket which covers all accommodation, meals and activities. You will just need to bring some extra cash if you wish to purchase an Ale at Little Creatures!

**Please be quick to book your tickets at**  
<http://www.peaceofmindfoundation.org.au/store/>

**Contact Bec Picone on 0411 382 457 for more information.**



# THANKS FOR YOUR SUPPORT

We are very grateful to those who organise a fundraising or awareness event – for BTAA or our alliance partners.

Special thanks to **Mel Johnson** of Bathurst for hosting another **Mel Goes Grey in May 2016**. Mel raised funds for both BTAA for support and for research for Brainstorm at RPA. She has raised over \$30k over her three events. Huge effort Mel and the **Penrith Panthers Bathurst** and all people of Bathurst who support you. Including but not limited to the **Mayor Gary Rush and the Deputy Mayor Ian North**.



*Image: Bathurst Mayor Gary Rush and Deputy Mary Ian North and his wife Lisa at Mel Goes Grey in May, 2016*

Thanks to the **Southern Cross Club Canberra**, for it's support of the ACT BT Support Network, and its grant to BTAA.

Thanks also to **Engineers Australia (ACT)** – who held a great trivia night for BTAA.

Thanks **Susan Dalliston** for nominating BTAA as Engineers Australia charity for 2017.

(Susan, who is the wife of our newsletter editor, author Mark, also walked the Larapinta Trail to raise awareness and funds for research via the **Cure Brain Cancer Foundation**. Big effort.)

Thanks **Paul Jurak, Kayakcameraman**.

Thanks again to our staunch supporter **Mel Tempest**, Ballarat Body & Soul Health & Fitness Studio owner – for another great fundraiser for BTAA. We really appreciate your ongoing support. See <http://meltempest.net/Blog/>

Big, big thanks to those who ran for BTAA, and their friends who supported them.

- **Em and Phil Duckett** ran the Gold Coast Half Marathon in July – 1:55:15 seconds.
- **David Corley** raised funds for BTAA in the WA Swan River Run in July.
- **Gemma** ran the **City to Surf** in Sydney, for a friend diagnosed in the UK.

- **Mark** is running the **WA City to Surf** for BTAA.
- **Adele** is running the **Bridge to Brisbane** very soon in honour of some important people in her life. So is **Chantelle Pithie**, running in support of her dad. And also **Toby Hodston**, running in memory of **Ned**.

Thanks to the following individuals who make a significant individual donation to BTAA since our last newsletter:

**Michelle Gregory, Joanne Gibbons, Sally Goodspeed, Clare Curwen-Walker, Clinton Leahy and Pat Wynn.**

Thanks also to **Debbie Pollard, Sylvia Gallagher**, and **Andrew Simpson** - our regular fortnightly donors to BTAA.

Particular thanks to new recruit **Pat Wynn** who came on board Team BTAA to assist with bookkeeping duties.

This newsletter is funded through the generosity of people who donated to **Thomas Daldy's** bicycle ride, in memory of his uncle Pedro Café. Thomas raised **\$4,560**. A great effort for a little boy who is only six. Thanks Thomas. Thomas likes cycling, trains, trams, lego and books. See Thomas's blog about his adventure here [www.tkd-ride.blogspot.com.au](http://www.tkd-ride.blogspot.com.au)

Set up your own fundraising page on our site here [www.btaa.org.au/page/21/fund-for-btaa](http://www.btaa.org.au/page/21/fund-for-btaa)

Or use the Everyday Hero channel – see our fundraisers running for BTAA here <https://nfp.everydayhero.com/au/brain-tumour-alliance-australia-btaa>

Or keep it simple and donate direct to our CBA bank account:

BSB: **062 900** Account: **10603153**

## USEFUL LINKS

Visit our web site to see more on **Clinical Trials**, get more information on brain tumours, find a list of brain tumour research organisations and support organisations here:

[www.btaa.org.au/page/29/useful-links](http://www.btaa.org.au/page/29/useful-links)

# Engineers Australia ACT Trivia Night



## 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!



Brain Tumour  
Alliance Australia



@BrainTumourAA



Search 'BTAA' for  
various videos

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