



THE OFFICIAL BTAA NEWSLETTER

# BRAIN CANCER ACTION MONTH EDITION 2018

MAY 2018 EDITION

**BTAA.ORG.AU**



## May Brain Cancer Action

**Ideas, Research, Hope.**

This newsletter was produced  
with the assistance of donations.

### INSIDE THIS ISSUE

**2018 Diary Dates**

**Report from the Chair**

**Brain Cancer Action Month**

**A Pacifists Guide to War  
on Cancer**

**Proton Therapy –  
An Australian Perspective**

**Tour de Cure Rides in for  
Patient Support Groups**

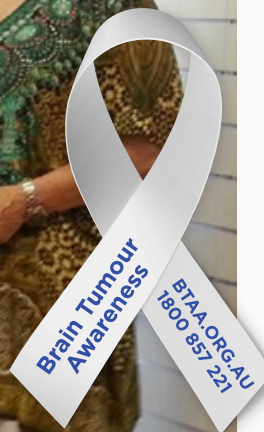
**Ghana-Australia Association**

**Outcomes Mixed from  
the Senate Inquiry**

**10th COGNO Annual  
Scientific Meeting**

**Saudi Student Support**

**Ghana-Australia  
Association  
Boosts Brain Tumour  
Support Services**



**Mel's "Go Grey In May" Dinner  
Hunter Brain Cancer Forum  
Geelong Patient and Carers Forum  
Melbourne Community Forum  
Sydney Brain Cancer Forum**



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



## SUPPORT IS AVAILABLE

### Sydney Brain Cancer Action Month Forum

**When:** 24th May 9.00 am to 3 pm

**Where:** Wesley Conference Centre  
220 Pitt St, Sydney NSW 2000

**Who:** All patients, carers, family, friends and allied health professionals and other interested members of the public are most welcome

**Cost:** No charge but you should register on the BTAA site as soon as possible

**Program:** Will be available soon and will be emailed to all those who register.

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](http://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](mailto:tsg@nswcc.org.au)

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

Email [btaa@shout.org.au](mailto:btaa@shout.org.au)

## 2018 DIARY DATES - IMPORTANT EVENTS

Event	Where	When
Hunter Brain Cancer Forum	West's New Lambton Bowling Club	Friday 4 May 2018 9.30 am - 2.30pm
Patient and Carers Regional Information Forum Geelong	Barwon Health Library 190 Myers St Geelong VIC	Thursday 10 May 2018 10.00 am – 3.00 pm
Brain Tumour Action Community Forum	Olivia Newton-John Wellness and Research Centre 145 Studley Road Heidelberg VIC 3038	Friday 11 May 2018 10.00 am - 3.00pm
Sydney Brain Cancer Action Month Forum	Wesley Conference Centre 220 Pitt Street Sydney NSW 2000	Thursday 24 May 2018 9.00am – 3.00pm
Mel's "Go Grey in May" Dinner	Bathurst RSL	Saturday 26 May 2018 6.30 to late
COGNO Cooperative Trials Group for Neuro-oncology Annual Scientific Meeting And Patient Forum	Brisbane	Sunday 7th October 2018 Tuesday 9th October
Walk Around the World for Brain Tumours	Various locations TBA	During International Brain Tumour awareness Week Saturday 20 October – 27 October 2018

# REPORT FROM THE CHAIR

**This issue is to mark Brain Cancer Action Month. I would like to acknowledge and reflect on the patients and families that are suffering because of brain tumours.**

I would also like to thank everyone who has worked so hard to raise funds for BTAA to enable us to reach our objectives.

## Support progress

We are one step closer to the goal of all patients being aware of BTAA support after surgery .

Neurology wards have been visited and we have spread the word to nurses about BTAA and delivering BTAA brochures. We are still seeking volunteers who would like to be involved in this activity so please contact me [chair@btaa.org.au](mailto:chair@btaa.org.au) if you would like to volunteer.

## Cancer Australia Project

A huge thankyou to all who have worked on the Project, translating brain tumour information into other languages, especially Tricia Berman.

## Website update

We are currently undertaking a review of all aspects of our website in order to improve the support we provide our members and subscribers. This includes upgrading the website functionality, modernising its overall design and making it more responsive to the needs of all visitors to the site. Part of that increased responsiveness will be the Patient Perspective Survey, our new web based survey project. It will give brain tumour patients, carers and family members an opportunity to provide their own perspective on the brain tumour journey, as well as providing us with valuable information to help us support, better the brain tumour community.



## The Third World Summit of Brain Tumour Patient Advocates

I represented BTAA at the Third World Summit of Brain Tumour Patient Advocates held in London in October 2017. BTAA received funding from IBTA to attend.

The Summit was attended by 84 participants from 30 countries. Participants included patient advocates (some of whom were patients or caregivers/former caregivers), medical and research professionals, and representatives of the pharmaceutical industry. The presence of a diverse group of stakeholders ensured that there was an educational, collaborative, and transparent focus on some of the biggest issues facing the international brain tumour community today.

Moves are underway to establish a closer affiliation with the Western Australia Brain Tumour Association. The BTAA has had a close association with this hard working WA group over the years and talks are underway on how the BTAA can expand our links while maintaining the autonomy of each group.

This newsletter was produced with assistance of donations from Melissa Johnson's Mel Goes Grey in May.

As usual there are many to thank who have contributed financially to our work through donations or fundraising events. Many thanks to:

Jenny Lloyd, Roger Harrison, Jenny Easey, Geoff and Linda Grimmer, Jenny Lloyd, Marcus Bennet, Amanda Coleman, Jessica Byrne. Your contributions are greatly appreciated.

**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.



## Brain Cancer Action Month

Throughout May organisations across Australia will hold events to raise awareness, provide information, highlight the need for support and make connections for members of the brain tumour community to mark Brain Tumour Awareness Month. Events are planned for Newcastle, Sydney, Melbourne and Geelong. BTAA members have been visiting neuro wards across Australia to ensure that staff and patients have access to the latest support materials and are able to contact the support organisations in their area. Information about each event is available in this newsletter.

The Australian Institute of Health and Welfare report of 2017 (Brain and Other Central Nervous System Cancer) emphasises the impact of these tumours. Each day six new cases of central nervous system cancer are diagnosed (a total of 2076 new cases each year). CNS cancer remains the leading cause of cancer death in children under ten. Despite many improvements in treatment and care there has been no improvement in the survival rate in the last thirty years and this still remains at a twenty five percent, five year survival rate. Even so called "benign" tumours cause significant morbidity and mortality each year.

There are many wonderful organisations, big and small, as well as individuals working tirelessly across the country to raise funds for research into brain cancer. Many of these people have either had a brain tumour or have had a loved one effected. Brain Cancer Action Month is also a time for us to recognise the very considerable efforts of these people and say thank you.

## A Pacifists Guide to the War on Cancer

During the last few months *A Pacifist's Guide to the War on Cancer* has been showing at various centres across the country. It is a funny, moving show about newfound friendships, pain and death, mundane treatment cycles, hairlessness and scars...with songs and dancing. International award-winning theatre company Complicité have dared to be different by creating an uplifting play with songs about this scary topic.



Following the performance there was a discussion with leading medical professionals to share latest research and innovations in cancer treatment. They were joined by cast members from the show.

The panel included : Prof Madeleine King, Cancer Australia Chair in Cancer Quality of Life; Director, Quality of Life Office, University of Sydney and member of the University's cancer research network, Dr Judith Lacey: Head of Supportive Care and Integrative Oncology at Chris O'Brien Lifehouse and Professor Janette Vardy: a medical oncologist working as a clinician researcher at the University of Sydney.

**BTAA Committee Member Stephen Newman and Gerry Tye also represented the brain tumour community as part of a patient forum following each performance. Hear Stephen's presentation here: <https://soundcloud.com/user-776983195/a-pacifists-guide-to-the-war-on-cancerm3>**

## Brain Cancer Action Week Community Forum Event in Victoria



The BCA Community forum will be held at the ONJ Cancer Centre in Heidelberg on Friday May 11th. The event will be held on Level 5, Olivia Newton-John Cancer Wellness & Research Centre, 145 Studley Road, Heidelberg (opposite Heidelberg train station).

All patients, carers and families are invited to be part of the conversation on the day with support groups, other patients and carers and leading brain tumour experts.

If you would like to have a display table, or information stand, please confirm with Brain Tumour Support on 9496 3315 or [btso@austin.org.au](mailto:btso@austin.org.au) by 4/5/18 at the latest. Please register to attend the event, regardless of whether you are attending as an "exhibitor" or for general admission.

**[www.eventbrite.com.au/e/brain-canceraction- community-forum-2018-tickets-44582951809](http://www.eventbrite.com.au/e/brain-canceraction-community-forum-2018-tickets-44582951809)**

**Dianne Legge - Brain Tumour Support Service 9496 3315**

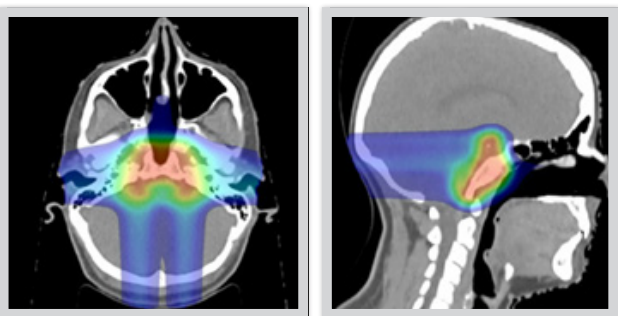
# Proton Therapy – An Australian Perspective

*Dr Hien Le Radiation Oncologist at Royal Adelaide Hospital*

## What is Proton Therapy?

Proton therapy is a type of radiation therapy (RT) in which charged particles are used instead of X-rays to treat tumours. Due to the nature of these charged particles, and how they deposit dose, the radiation is able to enter the patient's body and stop close to the tumour and spare significant amounts of healthy tissue from excess exposure<sup>1</sup>.

Proton beams have been explored as an option for radiotherapy since the 1950's. Early clinical use focused on paediatric tumours, where damage to healthy tissues can result in long term side effects and growth problems. For adult tumours of the head, neck and central nervous system, benefits have been demonstrated as tumours can be adjacent to extremely radiosensitive organs<sup>2</sup>. Historically, proton therapy has been used prolifically for the treatment of diseases at the base of skull, as they require high doses for sterilisation and are in very close proximity to a number of critical organs like optic nerves, brain stem and normal (uninvolved) brain tissues<sup>3</sup>. Recently, significant advances in technology have enabled proton therapy to expand its application to tumours of the lung, abdomen and pelvic organs. There are many ongoing important prospective clinical trials around the world studying the clinical benefit of particle therapy in a number of tumour types.

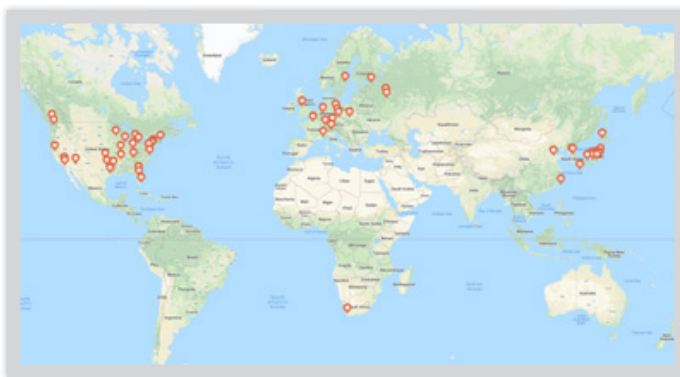


**Figure 1: Examples of proton dosimetry for transverse and sagittal views of the same adult patient with a diagnosis of a skull base chordoma, receiving 74 Gy in 37 fractions. Images courtesy of Royal Adelaide Hospital.**

## Proton therapy around the world

Proton therapy has been used to clinically treat cancer since the 1950's with approximately 150000 patients treated internationally as of December 2016<sup>4</sup>. Worldwide, there are 69 proton therapy centres in operation, 43 centres in construction and 22 centres in the planning stage as of March 2018<sup>5</sup>.

Below is a world map of proton centres around the world that are operational or in construction, showing in the majority in operation in North America, Europe and Eastern Asia.



**Figure 2: World map view with current and in construction proton centres marked in red (www.ptcog.ch, 2018).**

## The Medical Treatment Overseas Program

The Medical Treatment Overseas Program (MTO) is an Australian Federal Government initiative that provides financial assistance to patients suffering from life threatening conditions, where overseas medical treatment is required and not available here in Australia. Given the rising awareness of proton therapy, there has been a significant increase in the number of patients investigating this pathway for treatment. A large number of these applications have been successful for a range of malignant and benign conditions on the basis that which proton therapy is considered the gold standard treatment and superior to standard forms of modern radiation therapy.

As of 2016, the submission of a comparative proton and photon treatment plan is a mandatory component of an MTO application<sup>6</sup>. These specialized plans are currently performed at the Royal Adelaide Hospital by a dedicated proton therapy multi-disciplinary team. Patients are referred to the group via an electronic referral process, with image and planning data supplied by the referring physician. A radiation therapist specialising in proton dosimetry creates a number of plans, at least one conventional photon plan and a proton therapy comparison, which are reviewed by a radiation oncologist and medical physicist. These plans play an important role in the decision making process, both by the MTO board, but also by the referring physician, as from this plan, they may be able to quantify the specific benefit if proton therapy was used<sup>7</sup>.

## The Australian Bragg Centre

In May 2017, the Australian Government committed funding to support the establishment of Australia's first proton therapy facility in Adelaide. The Australian Bragg Centre for Proton Therapy (ABC) ([www.australianbraggcentre.com](http://www.australianbraggcentre.com)) will be housed in the South Australian Health and Medical Research Institute (SAHMRI 2) ([www.sahmri.com](http://www.sahmri.com)), adjacent to the new Royal Adelaide Hospital ([www.rah.sa.gov.au](http://www.rah.sa.gov.au)), and is expected to begin operation in 2020. Given that currently, patients requiring treatment with proton therapy are required to travel overseas, an Australian centre will no doubt ease the burden for many cancer patients. The ABC will also provide many more patients, the option of proton therapy treatment, resulting in a greater spectrum of treatment. The nature of proton therapy provides a unique opportunity for collaboration amongst a range of disciplines, which will enable the ABC to not only deliver world class proton therapy treatment, but establish itself as a world leader in treatment and research.



Figure 3: A visualization of the SAHMRI 2 building (second from the right), next to the original South Australian Health and Medical Research Institute (SAHMRI) ([www.australianbraggcentre.com](http://www.australianbraggcentre.com)).

## Proton therapy research at the Royal Adelaide Hospital

In 2014, a proton therapy working group was established at the Royal Adelaide Hospital (RAH), consisting of radiation oncologists, medical physicists and radiation therapists. While initially the focus of the group was to increase skill level and education surrounding proton therapy, a natural extension of the project has been toward research, especially in dosimetric comparative planning.

The RAH is currently undertaking research in many aspects of proton therapy such as proton tomography, the radiobiological effects of proton therapy, retrospective dosimetric comparisons and the social and economic factors of proton therapy. Several multi-institutional comparative projects are currently underway, comparing proton dosimetry to various highly specialized photon delivery methods to a variety of anatomical sites.

Many outcomes of this research have been presented at national and international conferences, with the latest presentation of a Prostate Stereotactic Ablative Body Radiation Therapy (SABRT) dosimetric comparison, at the Radiological Stereotactic Society meeting in the US in November 2017. The group is also working toward a number of publications of its research. The RAH intends to continue its multi-faceted research, with scope to increase the research portfolio in the lead-up to the opening of the first Australian proton therapy centre.

<sup>1</sup> Linz, U 2012, Ion Beam Therapy, Springer-Verlag Berlin Heidelberg, Jülich, Germany

<sup>2</sup> Alberta Health Services. Clinical Practice Guideline RT-002 Version 1. Proton Beam Radiation Therapy. 2013. [www.albertahealthservices.ca](http://www.albertahealthservices.ca)

<sup>3</sup> The Royal Australian and New Zealand College of Radiologists, 2015, Faculty of Radiation Oncology Position Paper on Particle Therapy. Available from <http://www.ranzcr.edu.au/resources/professional-documents/guidelines>

<sup>4</sup> Particle Therapy Co-Operative Group, 2016, Particle Therapy Patient Statistics. Available from [https://www.ptcog.ch/archive/patient\\_statistics/Patientstatistics-updateDec2016.pdf](https://www.ptcog.ch/archive/patient_statistics/Patientstatistics-updateDec2016.pdf)

<sup>5</sup> Particle Therapy Co-Operative Group, 2018, Particle Therapy Centres, <https://www.ptcog.ch/index.php>

<sup>6</sup> Department of Health Medical Treatment Overseas Program, 2018, <http://www.health.gov.au/internet/main/publishing.nsf/content/strategicpolicymto.htm>

## BTAA Fact Sheets Updated

**Mark Dalliston, a regular contributor and editor of this newsletter, has undertaken an extensive review and update of the Brain Tumour Fact Sheets that are available on the BTAA website. The update of the 80 Fact Sheets will make the valuable resource more relevant and available to a wider audience. As well as editing the language, spelling and punctuation used, Mark also referred some to an Oncologist for fact checking and update.**

Mark, who is also a brain tumour survivor, devoted almost a year of work to make sure that Australians have access to the best information possible. Many thanks from the whole BTAA team go to Mark on this very valuable contribution.





## Tour de Cure Rides in for Patient Support Groups

The Tour de Cure, Riding to Cure Cancer, team recently visited Canberra and presented a cheque for \$10,000 to support development of a national brain tumour support network. Riders on the tour stopped for a well-earned break at the Pavilion Hotel in Forrest and BTAA committee members attended for the presentation of the cheque.

The funds will be used to support and train leaders to ensure that Brain Tumour Patient Support groups are operating in all capital cities and major regional centres across Australia. Currently support group coverage is patchy, and even some capital cities do not have an active group. We hope to use this money to build the network of support groups in areas currently without support.

Tour de cure was established in 2007 when three mates, Geoff Coombes, Samantha Hollier-James and Gary Bertwistle decided to focus their efforts on helping finding a cure for cancer. They used their professional skills to create a program of bike rides to raise money for pioneering cancer research. Since 2007 11 signature tours and many other smaller rides have been run, usually more than 10 days and 1000 km in length, and many thousands of riders have taken part. The Tour de Cure has a goal of raising 7 million dollars for 2018.

Congratulations to the fabulous Cure de Tour team and all of the riders and those who donate to this wonderful cause.

Want to participate or donate? Go to: [www.tourdecure.com.au](http://www.tourdecure.com.au)

## Mark Hughes Foundation Award

Newcastle and Hunter Brain Tumour campaigner Mark Hughes was awarded the Citizen of the Year at the Newcastle 2018 Australia Day Awards for his contributions to brain cancer awareness and research. Mark said "There are so many wonderful people in the community making a difference and I am very honoured to receive this award. A very special mention to our MHF team, volunteers and supporters!"

Mark, a former NRL footballer and his team have been making a huge difference to the lives of patients, family and friends in the greater Hunter district. Congratulations to Mark and his team for this well-deserved honour.



## Canberra Couple Turn on the Christmas lights in Support of Brain Tumour Patients

Canberra couple, Roger and Kay Harrison, lit up their suburban Canberra street last December with an awesome display of Christmas lights. The lights made a spectacular display, attracting many people from across Canberra and bringing smiles to the faces of adults and children alike.

The Harrison's raised over \$2000 to assist the work of the BTAA in providing vital care and support for brain tumour patients and families across Australia. In addition, a further \$1460 was raised for Dainere's Rainbow Brain Tumour Support Fund which assists research to improve the outcomes of children diagnosed with brain tumours. And another \$1,300 was raised in support of local and overseas organisations helping



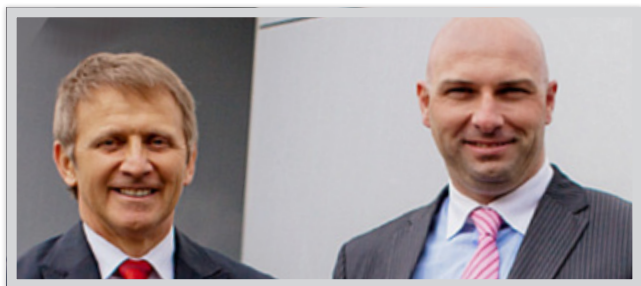
disadvantaged families and children in Vanuatu, Ghana and Canberra.

In what is an annual event, the Harrison's Christmas lights will be turned on again, with even more lights, as well as a choir singing carols on Saturday nights, from 1-26 December this year.

The BTAA will once again be a beneficiary of this wonderful event. The address is 17 Middleton Circuit, Gowrie, Canberra. Mark it in your diary now.

**Some of the home-made craft available at the Christmas light show.**

## Vanzwan Accounting's Magnificent Support

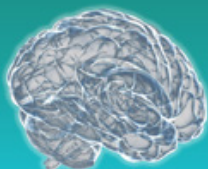


Local Canberra accounting firm Vanzwan Accounting Plus has once again provided some fantastic support for the BTAA at its annual client charity golf day and fundraiser.

A cheque for over \$12,000 was presented to chairperson, Catherine Hindson by Peter Vanzwan and David Boucher just before Christmas. Despite the rainy weather on the day, the Vanzwan team still managed to raise a very significant amount of money that will go a long to ensure that every brain tumour patient, carer and family member has the support that they need.

Great work and thanks to Peter and David and the whole Vanzwan team who work so hard every year to make this happen.

You can contact Vanzwan Accounting Plus at [www.vanzwan.com.au](http://www.vanzwan.com.au)



## Brain Cancer Action Week

### Patient & Carers Regional Information Forum

This forum will provide information about the developments in the field of brain cancer.

It will be a fantastic opportunity to meet others in a similar situation.

**Sessions include:**



- Developments in personalised brain cancer treatment and research
- Practical challenges - returning to work, travel insurance and accessing early superannuation
- Debunking Palliative Care
- Dealing with uncertainty
- Personal stories from patients and carers.
- Explore information stalls with valuable supportive care resources during the breaks.

**Thursday 10th May**  
10am to 3pm, 9:30am registrations open  
190 Myers St, St Mary's Hall (Barwon Health Library)

*This is a free event and all are welcome: Patients, carers or anyone interested in learning more about brain cancer.*

Our presenters are experts in neuro-oncology, brain tumour research, radiation oncology, palliative care, counselling, occupational therapy, law and finance.

Hosted by Peace of Mind Foundation, in conjunction with Barwon Health.  
Register here: <http://www.peaceofmindfoundation.org.au/brain-cancer-information-forum/>  
RSVP by Monday 7th May



# We are getting closer to launch...

Tricia Burman

## We are getting closer to the launch of two new resources for brain tumour patients, family and carers!

In 2016, BTAA was awarded some funding by Cancer Australia to undertake a three year project to develop new brain tumour resources including for those working with culturally and linguistically (CALD) different communities. We are now well underway and have two new resources about to be translated.

In late 2017, the project undertook 7 focus groups to obtain feedback from patients, carers and family and from clinicians on the two proposed resources. The Focus Groups were held in Brisbane, Sydney and Melbourne. They were conducted by Judith Meicklejohn, ably assisted by Dr Danette Langbecker and Diane Legge. The outcome was overall support for the two resources with some amendments made following the consultation.

Polaron (a Melbourne translation business) is now developing design options for the two resources and will commence translating/testing them. They will be available in Easy English and up to 10 other languages. BTAA is particularly excited about making the new resources easily available on its website so that patients and others can easily print and take to medical consultations etc. All Australians irrespective of their cultural background will be able to get access information in their preferred language about the brain tumour journey and keep a record of their diagnosis etc.

BTAA would like to give special thanks for the support it has received from the members of the project's Steering Committee – Dr Danette Langbecker (U Qld), Diane Legge (the Austin), Dr Jonathon Parkinson (U Sydney), and Sally Payne (IBTA). In particular, BTAA would like to acknowledge and thank Dr Langbecker who organised the Ethics Committee approval and who oversaw the consultation process. And thank you to the Project Team who have worked tirelessly to get the resources ready for translation – Tricia Berman, Catherine Hindson, Janet Micallef, Susan Pitt, Philip Steel, Rigoula Roussakis, and Annabelle Wilson.

A very big thank you for all those who participated in the consultation focus groups in September 2017. Our patients, family and carers gave of their time freely and with enthusiasm. Thank you so much as we were truly delighted with the response and positive feedback.

Stay tuned as we will alert you to the new resources when they are ready and hope to have a special launch so everyone can get involved in using them.



Tricia Berman (centre) is manager of the Cancer Australia Project but can also be found helping at newsletter mail out.

## Hunter Brain Cancer Forum 2018

4 May 2018, 9:30 am

**You are invited to attend the second Annual Hunter Brain Cancer Forum, supported by the Mark Hughes Foundation and the NSW Cancer Council.**

This Forum is specially designed to provide information, resources and insight into primary braincancer. Come and hear from leading medical professionals including neurosurgeon Dr Mitchell Hansen, Medical Oncologists Dr James Lynam and Dr Craig Gedye, Radiation Oncologist Dr Michael Fay and End of Life Nurse Practitioner, Jeanette Lacey.

**The Forum will include information stalls by Brain Tumour Alliance Australia, CanTeen, Cancer Council, Hunter Cancer Biobank and more.**

**When:** Friday May 4, 2018. 9.30am - 2.30pm

**Where:** Wests New Lambton Bowling Club

**Cost:** FREE

**Food:** Morning tea on arrival and lunch will be provided free of charge

**Accom:** Discounted room rates available at Wests New Lambton

**To attend the forum, please register online (<https://secure.hmri.org.au/hunter-brain-cancer-forum>) or call 1300 993 822 and indicate how many people you would like to register to attend, or if you live in a rural area and would like to utilise teleconferencing.**

# Patient Perspective Trial To Put Patient Care First

Stephen Newman

The Patient Perspective survey was borne out of an idea that the patient is best placed to determine whether the outcome of treatment has been successful. This idea is not to downplay or diminish the role of doctors, nurses, oncologists or the broader medical community, in fact it's designed to enhance the medical community's role by providing valuable information about what works and what can be improved.

Patient Perspective is a web based survey and journal for patients and their carers to record every aspect of their brain tumour journey, from diagnosis, to treatment, recovery, medication, quality of care, through quality of life to brain tumour awareness, through to their own engagement with the broader brain tumour community.

For years, patients have been given information, most of it helpful, vital and life saving, but until recently they have never had an avenue to talk about their journey and to provide the sort of information and feedback to the medical and broader community about what it is that will help them have a longer lasting recovery and a better quality of life.

Patient Perspective approaches patient care from the viewpoint that the person with the lived experience is the best person equipped to explain what works and what doesn't work for them. We want to capture as much of that lived experience as possible so that we can have better information, so that we can better support, represent and advocate on behalf of everyone on the brain tumour journey.

The concept of patient reported outcomes is not a new idea, however, for many patients wanting to tell their story, finding valuable information and having a voice within the maelstrom of information and discussion, particularly on social media, has often been a frustrating one, as numerous other very worthy causes suffocate any contribution they wish to make.

Patient Perspective will collect and collate the information that patients, carers and family members provide it. We will be able to report back to the brain tumour community information about not only what is working and what could be done better but also a narrative about the things that are important to them.



Committee members Billy Williams and Stephen Newman

If Patient Perspective does nothing else other than provide a place for brain tumour patients and those close to them to record their journey then it will have served a valuable purpose. We see it, however, going much further than that.


Not only can this information be used to assist in the support of everyone on this journey but it can help to advocate on the brain tumour community's behalf, not only to the medical community but also to governments, as we seek to find ways to gain a deeper knowledge into what we all know is a debilitating and life changing disease.

The patient or carer will be able to use Patient Perspective to edit or update their own journey as well as gain both an overall and a detailed view of the brain tumour community and how we are travelling. Patient Perspective will also, hopefully, reassure patients and their families that they are not alone.

The scope for Patient Perspective is limited only by our community's willingness to participate. We hope to add functionality to it, as patients provide feedback to us and telling us what is important to them and thereby helping us provide the best support that we can, whether it's advocating for patients, supporting patients, or connecting patients. We want patients and carers to help provide the roadmap for where we go from here.

**If you would like to participate in the Patient Perspective pilot program, please contact [enquiries@btaa.org.au](mailto:enquiries@btaa.org.au) and we'll be pleased to provide you details of how you can take part.**





# A Question of Balance

Stephen Newman

Photo:  
Katrina Lim

**I mumble “I’m now getting up” to myself as I raise my frame from the sofa, as if to reinforce the notion that I must stand. It’s not a matter of not having the strength, I have that now, cycling has helped in that regard, to return power to my legs. The issue at play here is balance, or the lack of it. The chance that I could launch myself skyward yet come a cropper half way through the trajectory, as I find the angle at which I am ascending to be somewhat askew of the strictly perpendicular, is at the forefront of my thinking, so I verbalise, as if to remind the god of gravity that I am still a little lacking in the stability department.**

Before I go on, I should preface my comments by saying that my intended audience for this missive is not the brain tumour community, they may read this and remark “tell me something I don’t already know”. It’s for anyone who may know a brain tumour survivor, or has met one, and who wonders what the fuss is about.

It’s been almost 18 months since my surgery, I have been making good progress, I am back driving my car, I get a good nights sleep, something foreign to me pre-surgery, my countenance has changed, I can do most of the things I would like to do, except ride my bike on the road but of course, it’s a small price to pay and there are benefits, being relieved of motorist angst not the least of them.

But of late, the pace at which I have been making progress has begun to take a toll. I have had to realise, the revelation is a startling one, that things on the outside betray the inner workings. For the past fews weeks the fogginess that I have so readily tried to describe has manifested rather more brutally than I had imagined it might. I have realised that brain tumour recovery, I suppose much like progress in any area, does not proceed in a straight line. Nothing about it is linear.

Without wanting to repeat myself, I’ve previously described mundane activities such as walking to the shops in terms of preparing for a final, making sure there’s a back up plan if the game day strategy somehow disintegrates. Walking at the moment is more difficult than it was 12 months ago. It shouldn’t be, it defies logic that it is, but that is the reality of it. I am finding the effort required to even walk the dog around the block is greater than that of getting on my bike and riding hard for an hour. The reason for this may also defy the reader’s logic but it’s a fact. This is simply the result of the kind of sustained energy and concentration required to prevent falling over, whereas when I’m on the bike, I’m, for all intents and purposes, strapped in. I don’t have to concern myself with staying upright, or well balanced, so as not to run into Mrs Johnston as she’s innocently perusing the Harris Farm fruit and veg.

What I may have considered in the past as being a bit of sport, crossing at a set of lights not specifically indicating to me permission to walk, I now consider plain fool hardy to even contemplate such a daring plan. I now wait, even if it takes another five minutes out of my day – yes, one can wait, around these parts, that long for pedestrians to be given the green light – for the next round of offers to come around so that I can cross the street in relative safety. I don’t care if it makes me look old, overly cautious or somehow infirm. I’m taking as many of the rash decisions out of the new normal equation as I can.

I have to build more common sense into living, and probably, you could observe and accuse me of being that way, overly cautious for a fit man such as myself. But I am beginning to appreciate what lurks around the corner if I go ahead and assume like I once did. That in itself is not such a bad thing when you stop and

consider it, the pause to consider, to slow down, to simply relax a little more.

I have just finished reading a book, written by a gentleman by the name of Henry Marsh. He was one of the U.K’s most pre-eminent neurosurgeons. Entitled Do No Harm, he exposes his career to the reader, admits faults and rejoices over triumphs. One chapter was devoted to what he described as the most difficult operation he’d ever undertaken. The tumour that he operated on was precisely the tumour I had, a Petroclival Meningioma, as with these, it’s the location that matters not just the tumour, benign as it was, although I am reminded by my fellow travellers that there is nothing benign about a brain tumour. His operation didn’t go so well. The patient lived but spent seven years bed ridden in a nursing home.

He stated, and bear in mind this is just his opinion and neurosurgeons, even the eminent ones, can be wrong, as Henry would concede, that brain tumour survivors very rarely fully recover. My response is that even if we don’t, and I don’t know whether I will, I certainly haven’t accepted that I won’t, we redefine our lives, what is normal, what is important, what is relevant.

That my surgery was a success, thanks largely to the skill and care of a quite brilliant human being and surgeon, makes me not care that I can’t spin my pedals up through Akuna Bay, or change a light bulb, or rise from the sofa without a groan, or take liberties with traffic, or pull on a pair of pants without some decent planning. What matters is appreciating the things that really matter, and now I must get up, slowly, deliberately and probably, if you’re watching, rather amusingly. My wife has bought cake and I need a cup of tea.

# GHANA-AUSTRALIA ASSOCIATION BOOSTS BRAIN TUMOUR SUPPORT SERVICES

**The Ghana Australia Association ACT has helped boost support for families affected by brain tumours with a cheque for \$10 500 to the Brain Tumour Alliance Australia (BTAA). The funds were raised at a dinner held in November, in honour of Mrs Lynette Williams who passed away in April last year from a glio blastoma multiforme (GBM).**

In thanking the Ghana -Australia Association, the Chair of the BTAA, Mrs Catherine Hindson, said the funds would be used to give further support to brain tumour patients and their families. 'Having known Lynette personally, I know she would be pleased that the funds raised will give much needed support to families devastated by the impact of brain cancer. By their very nature, brain tumours affect the most vital organ of the body and the unique personality of each individual,' Mrs Hindson said.

The Cooperative Trials Group for Neuro-Oncology (COGNO) in Australia have agreed to establish an annual prize of \$1000 each year for ten years to encourage further research into supportive care for people living with brain tumour and their families. The inaugural prize winners of the BTAA Lynette Williams Award will be announced at the annual scientific meeting of COGNO to be held in Brisbane in October.

Lynette Williams was a close friend of Ghana during a five year period till 2013 when she was posted there with her husband. Lynette worked tirelessly in support of disadvantaged and disabled children. Half the funds raised at the dinner will go to support the work of the Orthopedic Training Centre (OTC) in Ghana, to provide specialised equipment at a day care centre for children with cerebral palsy.



*Ms Mona Moutrage, President of the Ghana Australia Association, Mr Billy Williams, and Catherine Hindson, Chair of the BTAA*



*Mr Ebenezer Banful from the Ghana Australia Society hands a cheque for \$12000 to Ms Catherine Hindson of the BTAA*

## 12th International Brain Tumour Awareness Week and the Walk Around the World for Brain Tumours (2018)

The 12th International Brain Tumour Awareness Week will be held from Saturday, 20th October to Saturday, 27th October 2018 inclusive. We encourage you to organise an activity which will contribute to increased awareness about brain tumours. It could be a walk, a picnic, an information seminar, a scientific conference, or the distribution of a media statement to draw

attention to the particular challenges of a brain tumour and the need for a special response and increased research effort. As well as taking place during the International Brain Tumour Awareness Week, the Walk Around the World for Brain Tumours runs from 1st January 2018 to 31st December 2018.

**Please register/report your Awareness Week/World Walk activity by completing an online form on the International Brain Tumour Alliance website**



## Adam Bruin's - In Memory of Adam

Adam passed away on November 14th 2017 after a struggle with a brain injury following his surgery for a brain tumour in 2014. Adam has touched the lives of many fellow brain tumour survivors across the globe.

Adam was an amazing father, his girls will miss their Daddy more than we can ever comprehend.

Adam was also a wonderful artist, musician and teacher. He has touched the lives of far more people than he could ever imagine.

Instead of sending flowers Adam wished for people to donate to his charity Brain Tumour Alliance Australia. So far \$1964 has been raised by donations from family and friends.



## Outcomes Mixed from the Senate Inquiry

Late in 2017 the Senate Select Committee delivered its report on Funding for Research into Cancers with Low Survival Rates with a focus on the impact of health research funding models on the availability of funding for research. The report is available at the Australian Parliament House website.

On 24 January, the Minister for Health, the **Hon. Greg Hunt MP** announced the Australian Government is supporting Australia's best and brightest medical researchers in their fight against rare cancers and rare diseases with a \$69 million boost

The funding included more than \$26 million for nineteen research projects as part of the landmark **Medical Research Future Fund's** (MRFF's) *Rare Cancers, Rare Diseases and Unmet Needs Clinical Trials Program*. This included funding for testing a vaccine to target glioblastoma and funding for evaluating the benefits of medicinal cannabis for people with advanced cancer, and define the role of the drug for patients with cancer in palliative care. The Minister also announced the members of the **Strategic Advisory Group** which will support the \$100 million Australian Brain Cancer Mission. The Mission is a partnership between the Federal Government, philanthropists, medical experts, patients and their families and it aims to double survival rates for people living with brain cancer over the next 10 years.

Members of the Strategic Advisory Group are **Professor Adele Green AC, (Chair), Professor Douglas Hilton AO, Ms Sarah Mamalai, Mr Dustin Perry, Ms Robyn Leonard, Dr Chris Fraser, Professor Mark Rosenthal, A/Professor Rosalind Jeffree, Professor Grant McArthur, Professor Brandon Wainwright, Professor Andrew Scott AM, Ms Michelle Stewart, and Ms Michelle Burke**. Commonwealth funding is allocated via the MRFF. The most recent MRFF Low Survival Cancers and Diseases (LSCD) Grant Opportunity closed on 18 April 2018. The grants were for a single clinical trial that aims to improve survival rates for Australians with a low survival cancer or other disease.

The Victorian Government responded to effective advocacy by the [Low Survival Cancers Alliance](#) on the need for additional funding for low survival cancer

research. The Victorian Government has announced \$1.5M of funding to low survival cancer research to be awarded through the Cancer Council's Grants-in-Aid program. This will likely equate to an extra five \$300,000 grants being awarded through this program. In addition, the Cancer Council of Victoria will be investing \$1m into low survival cancers research.

BTAA notes that the Senate Inquiry and its recommendations fully covered the anguish of carers and families of a brain tumour patient and their need for supportive care, as well as care for the patient. Whilst BTAA welcomes the additional funding for those in the scientific and research community involved with lab work and clinical trials we note the need for research into supportive care delivery.

Those preparing grant applications are encouraged to consider whether their research would benefit from having an element of supportive care research in the research design.

Those preparing or commenting on grant criteria are encouraged to remember the need for research dedicated to supportive care for those living with brain tumours.

**Mel's "Go Grey In May" Dinner**

**When:** Saturday 26th May 6.30 pm

**Where:** Bathurst RSL Club

**Tickets:** \$90 including a 3 course meal.

*Tickets will be available from the RSL Club reception.*

## Community Has Access to World Experts at COGNO Forum

**In conjunction with the 10th COGNO Annual Scientific Meeting in October 2017, the BTAA hosted the Melbourne Community Education Forum.**

COGNO is the Cooperative Trials group for Neuro-oncology and each year it invites leading doctors and scientists from across the world for this major neuro-oncology conference. Amongst the speakers in 2017, Professor Daniel Kelly (John Wayne Cancer Institute California) spoke about new approaches to keyhole and endoscopic surgery for brain and skull base tumours, Associate professor Michael Brack spoke about advances to tailored radio oncology and Professor Patrick Wen ( Dana Faber Cancer Institute Boston) spoke about tailored drug therapies for brain tumour patients.

**Topics included; Tailoring Therapies for Brain Tumour - Challenges and Opportunities, Trials Update, Novel treatment strategies, Seeing the Target - Updates in Diagnostics and Imaging, Hitting the Target - Updates in Treatment, Treating the Patient, Not the Tumour.**

The Community Education Forum was held on the afternoon prior to the COGNO conference and this allowed patients, carers, family and members of the

public to hear some of these international speakers and ask questions about treatment.

Speakers included:

**Professor Patrick Wen:** An international perspective on targeted therapies and clinical trials.

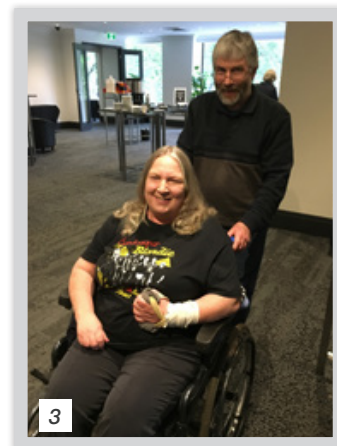
**Professor Daniel Kelly:** The role of surgery in the age of personalised medicine.

**Professor Jennifer Philip:** What's the Buzz – Medical Cannabis and Brain Cancer

Audience members were then able to ask questions of this panel.

COGNO and the Patient Forum will be in Brisbane in 2018. The BTAA will provide some part assistance for accommodation and travel for patients and carers who wish to attend as well as travel grants to medical professionals. See more information in this newsletter.

Many thanks to our speakers who took time out from their very busy schedules to attend the forum and the Olivia Newton-John Cancer Wellness and research Centre



1. Professor Daniel speaks about keyhole surgery for the brain.
2. Professor Daniel Kelly, Dr Zarnie Lwin and Professor Patrick Wen at the Patient Forum.
3. Two of the participants at the Forum
4. Susan Pitt, Dr Mark Rosenthal and Hunter advocate Kay Duffy at COGNO.



## BTAA Member Sponsorship and Educational Grants COGNO 2018

**BTAA offers two types of sponsorship to our financial members.**

**Educational Grants** are available to our financial members who are **nurses and other allied health professionals**, or **researchers**, with a particular interest in supporting people living with brain tumours. Grants are available to attend events like COGNO in Australia and SNO, ISPNO and ASNO internationally. Download the guidelines from our website.

BTAA reimburses expenses up to **\$600** for a national event or **\$1,500** for an international event, upon presentation of receipts for travel, accommodation or registration. More costs may be available at the discretion of the BTAA committee.

Thanks to the Nicola Scott Educational Trust for the educational grant funding.

BTAA also provides grants to our financial members who provide **peer to peer support**. Financial assistance is provided to enable our members to attend the BTAA National Summit, held in conjunction with COGNO. e.g. Those who run support groups, those who volunteer for the Cancer Connect Service, those who manage a dedicated online support page.

Grants are on a case by case basis and depend on the distance to be travelled, other income sources etc. These grants are paid for out of BTAA's donation revenue. Thank you to our donors.

**It is easy to become a financial member of BTAA - see : [btaa.org.au](http://btaa.org.au)**

**Email [btaa@shout.org.au](mailto:btaa@shout.org.au) cc [Catherine@hindson.org.au](mailto:Catherine@hindson.org.au)**

The 2018 COGNO annual scientific meeting will be held in Brisbane this year in October. The BTAA offers sponsorship and educational grants for nurses, allied health professionals and researchers to attend.

**Event**  
11th COGNO Annual Scientific Meeting

**When**  
Sunday 7th – Tuesday 9th October 2018

**Where**  
Brisbane, Australia

The Brain Tumour Alliance Australia will also conduct a patient forum in conjunction with COGNO. Small travel grants are available to assist patients, carers and their families to attend. See the BTAA website [www.btaa.org.au](http://www.btaa.org.au) for more information.

## IBTA Provides Medical Updates

**All BTAA subscribers automatically receive a comprehensive worldwide up to the minute technical and medical update in the International Brain Tumour Alliance e-news. A link to all of these articles on the IBTA e-news can be made through the BTAA website. Recent posts in their e-news included:**

- Phase III study concludes that Optune (Tumor Treating Fields) improves survival in newly diagnosed glioblastoma
- Optune therapy for newly diagnosed glioblastoma has been approved for government reimbursement in Japan, Novocure announces.
- Bevacizumab (Avastin) granted full approval by US FDA for recurrent glioblastoma
- Price of chemotherapy drug Lomustine
- Biosimilar medicines patient information leaflet now available in 23 languages
- More highlights from SNO 2017
- Understanding why 'mini-brain organoids' could accelerate personalised treatment in brain tumour research
- Many high-grade glioma patients do not receive adequate access to end-of-life care, research finds
- New clinical guideline recommends palliative and supportive care to start soon after diagnosis
- Ketogenic diet triggers genetic changes in glioblastoma that may enhance chemo and radiotherapy, study suggests
- Review article examines how low oxygen levels stimulate glioblastoma growth
- New brain tumour drugs are held back by blood-brain barrier transporter, findings reveal
- New clinical scoring system proposed for re-irradiation of recurrent glioma
- Brain tumour-staining fluorescent dye used alongside novel probe has encouraging results, preliminary data shows
- Study suggests PLK4 inhibitors have potential as a treatment for childhood medulloblastoma and atypical teratoid/rhabdoid tumours (AT/RT)
- Glioblastoma tumours with 'Glut3 Addiction' are highly sensitive to cilengitide, research finds
- Language impairments following low-grade glioma surgery tend to improve over time, study finds
- Research identifies potential drug target in glioblastoma self-protective mechanism
- Phase III trial of Diffusion Pharmaceuticals' TSC in newly-diagnosed glioblastoma now enrolling
- Trial of INSIGHTEC's 'Exablate Neuro' in brain tumours approved by US FDA
- First patient treated with DNatrix DNX-2401 in paediatric DIPG phase I trial
- Update on phase II trial of DelMar Pharmaceutical's VAL-083 in recurrent glioblastoma



*The Saudi Arabian Cultural Attaché, Saudi Arabian Cultural Mission staff, Saudi Arabian students and members of the BTAA at The Canberra Hospital*

## Saudi Student Support

Recently the Embassy of Saudi Arabia contacted members of the BTAA seeking assistance to visit brain tumour patients at the Canberra Hospital on International Volunteer Day. The Saudi Arabian Cultural Mission supports Saudi students studying in Australia and seeks to build cultural and educational bridges between the countries and especially for their students.

The Saudi Cultural Attaché and the Saudi university students visited patients and provided a package of gifts for each patient. Patients were pleased to talk and explain their journeys to the visitors and the students were able to gain an insight into Australian culture and the hospital system. BTAA thanks the Saudi Embassy for the visit and hopes it can be expanded in the coming year to other universities across Australia.



## SPREAD THE WORD!

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

**1800 857 221**  
**www.btaa.org.au**



Brain Tumour  
Alliance Australia



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Search 'BTAA' for  
various videos

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