



THE OFFICIAL BTAA NEWSLETTER

INTERNATIONAL BRAIN TUMOR AWARENESS WEEK EDITION 2017

OCTOBER 2017 EDITION

BTAA.ORG.AU

This newsletter was produced with the assistance of donations.

INSIDE THIS ISSUE

2017 Diary Dates

Report from the Chair

**11th International Brain Tumor
Awareness Week 2017**

Lifeshouse support group

Senate Committee

2017-2018 BTAA Committee

Cancer Australia Project

Fundraising Activities

Nicola Scott Educational Grants

Hannah's Story

The AIM BRAIN project

Mel Goes Grey in May 2017

**Peace of Mind -
Women's Retreat**



**Senate Committee
Unique Opportunity For
Improved Low Survival
Rate Cancer Outcomes**



Brain Tumour
Awareness
BTAA.ORG.AU
1800 857 221



**IBTA Week
Melbourne Community
Education Forum**



Brain Tumour
Alliance
Australia



@BrainTumourAA



Search 'BTAA' for
various videos

ABN 97 733 801 179

Incorporated in the ACT: AO45837

Freecall number 1800 857 221



SUPPORT IS AVAILABLE

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

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

Cancer Connect telephone (13 11 20)

Brain Tumour Patients Telephone Support Group
Freecall 1300 755 632
Monday - Friday 9am - 5pm
or email tsg@nswcc.org.au

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

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

2017 DIARY DATES

21 – 28 October 2017
International Brain Tumour Awareness Week
<http://www.btaa.org.au/events>

22 October 2017
Melbourne - Patient/carer forum
<http://www.btaa.org.au/events>

23-24 October 2017
Melbourne – Cooperative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting
<http://www.cogno.org.au/>

29-31 October 2017
14th Annual Meeting of the Asian Society for Neuro-Oncology (ASNO 2017)
<http://theibta.org/events-and-conferences/>

11 November 2017
Canberra - Ghana-Australia Association dinner for Lyn Williams
<http://www.btaa.org.au/events>

16-19 November 2017
San Francisco, California, 22nd Annual Scientific Meeting of the Society for Neuro-Oncology (SNO 207)
<http://theibta.org/events-and-conferences/>

25-26 November 2017
Cape Town, South Africa.
Paediatric Brain Tumour Workshop
<http://theibta.org/events-and-conferences/>

DONATIONS

Special Thanks to the following

Significant individual donations:

- Everyday Hero fundraisers for BTAA.
- Andrew Landers Shave for a Cure
- Nicola Scott Fundraising Dinner for the Nicola Scott Educational Trust
- Lynsey Watson Pin up girl
- Vanessa Moore, in honour of Mick McCall
- David Stratton Celebration of Kerrie's Life

Thanks also to:

- Debbie Pollard
 - Sylvia Gallagher
 - Andrew Simpson
- who contribute regularly.

REPORT FROM THE CHAIR

This year has once again been a very busy one for our dedicated volunteers who seek to support, inform, represent and connect brain tumour patients, their families, carers and members of the brain tumour community across Australia.

As well as our daily commitment to provide a 24hr telephone support service and the provision of information packs to newly diagnosed brain tumour patients and families, a great deal of effort has been addressed to ensuring that the brain tumour community voice has been heard at the Senate Select Committee into Low Survival Rate Cancers, and into developing our resources to ensure that they are more inclusive for our modern-day Australia.

Thanks must go to our committee members during the year 2016-17

- Chair – Catherine Hindson
- Vice Chair – Philip Steel
- Secretary – Patricia Berman
- Assistant Secretary – Susan Pitt
- Treasurer – Pat Wynn.
- Ordinary Committee Members – Rigoula Roussakiss, Janet Micallef, Julia Robertson, Sally Payne (resigned January 2017), Alice Payne, Pam Hubner, Mark Dallison and Mel Tempest

And our unelected honorary positions

- Public Officer – Patricia Berman
- Research – Nicola Sheehan
- WA State Coordinator – Diana Andrew
- Advisers – Denis Strangman and Matthew Pitt

Very special thanks to our office manager, Trish Greenaway, who volunteers each week to ensure that every request for information and every enquiry is promptly and thoughtfully acted on.

Activities in 2016 -2017

BTAA has continued to develop our four identified priority areas:

- **SUPPORT** – supporting the needs of all brain tumour patients and carers and their families through our services, resources and programs
- **INFORM** – develop and provide high quality information in a range of formats to empower participation in decisions about treatment and care
- **REPRESENT** – advocating and representing the BTAA community to ensure their voices are heard and for improved care and research
- **CONNECT** - connecting with people and organisations in the brain tumour community

BTAA continues to investigate brain cancer support material, as part of our agreement with the Cancer Australia grant in 2016, to develop relevant material for people from Culturally and Linguistically Diverse backgrounds. This project is led by Tricia Berman. Ethics Committee approval to conduct the project Focus Group research was granted by the University of Queensland with gratitude to Dr Danette Langbecker who oversaw the process. Focus groups with patient and carer groups commenced on 1 September. Particular thanks also to Di Legge. Also thanks to Sally Payne, Jonathon Parkinson, Rigoula Roussakiss, Janet Micallef, Philip Steel and Susan Pitt.

The brain tumour primers we have used in our information packs, sourced from the American Brain Tumour Alliance, have been out of print awaiting the inclusion of information based around new treatments such as immunotherapy, and this has not yet been resolved.

BTAA has a newly formed Brain Tumour Support Group that meets in Sydney. The group meets on the 1st Friday of the month at Chris O'Brien Lifehouse cancer hospital, Camperdown. The group is coordinated by Alice Parsons and she is supported by Gerry Tye and Steve Newman. There is live streaming of the guest speakers to Bathurst's Daffodil cottage where brain tumour patient and interested people gather. A huge thank you to Melissa Johnson for requesting this service and to Gerry Tye for making it happen at the Sydney end.

We continue to advocate for specialised Brain Tumour Care Coordinators in a range of forums.

BTAA provided a strong consumer voice through a submission to the Senate Select Committee into Funding for Research into Cancers with Low Survival Rates. BTAA was given the opportunity to appear before the Senate in June. Thanks to Tricia and Susan for developing our submission, to Nicola Sheenan who encouraged so many to make a submission. Philip, Tricia, Alice, Nicola and myself appeared before the Senate on 8th June 2017. Submissions were also submitted and heard by Susan Pitt, Denis Strangman and Billy Williams.

Other activities included:

- Continues to provide an 1800 Freecall number for brain tumour patients and caregivers
- Mailed two newsletters to more than 1,500 subscribers to mark International Brain Tumour Awareness Week 2016 and Brain Cancer Action Week 2017.
- Emailed our e-news to more than 1,500 subscribers.
 - » Mailchimp tells us that around 36% are opened – a high rate.
- Managed the BTAA Facebook page with over 2,768 Likes, and monitored social media and google news.
- Assisted with the attendance of Dr Mary Lovely at COGNO and hosted the 4th National Summit of brain tumour support groups in Sydney during COGNO's 2016 ASM.
- Represented the brain tumour community at AMC review of the Royal Australasian College of Surgeons, along with Rare Cancer Forum, Garvan Genomic Cancer Medicine Program, Cancer Voices Australia, and Palliative Care Australia Forum.

- Worked with the NSW Oncology Group and Cancer Council NSW and in Victoria the Austin, Cure Brain Cancer Foundation to conduct patient/carers forums during Brain Cancer Action Week May 2017.
- Auspiced the ACT Brain Tumour Support Network meetings each month led by Philip.
- Continued with television community service announcements around Australia.
- Provided Educational Grants to Registered Nurses, Allied Health Professionals and Researchers involved with patients with brain tumours. Led by Catherine.



Catherine Hindson
Chair BTAA Canberra

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

The BTAA finances for the 2016-17 financial year

Year	Revenue	Expenses	Net operating balance
2016-17	\$97179,56	\$59,227.92	\$246,435.35 NB

NB The above operating balance includes the grant of \$85K received from Cancer Australia for the Supporting People with Cancer and the \$75K committed by BTAA to produce new information resources for brain tumour patients including those from Culturally and Linguistically Diverse backgrounds. This money is to be spent over the period 2015-16 to 2018-19 with major expenditure in the years 2017-18 and 2018-19.

Sydney Lifehouse Support Group Success

For many of us, associating the word energy with a group of people gathering to discuss issues related to their own brain tumour journey might not be the first word that springs to mind.

However, the Sydney Brain Tumour Alliance Peer to Peer Support Group belies this notion. There is energy, shared experience, inspiration and an acceptance of each persons journey at every meeting. Conversation spills out into the hallway at the conclusion of our meetings, where members support each other with tips, insights, ideas, as well as a listening ear, about how we might tackle our own particular situation.

We meet on the first Friday of each month at the Chris O'Brien Lifehouse at the RPA, we welcome brain tumour

patients and their families, because we recognise that family members are an important part of that journey and where our guest speakers have ranged from Gail O'Brien herself, to a neurosurgeon, an exercise physiologist, a yoga instructor, an art therapy teacher, to a GBM survivor. All of these guests have provided information or inspiration, or both, to help us navigate the path we find ourselves on. Most meetings also include a video hookup with a regional centre so that our friends from outside Sydney can contribute and listen to the insights of our speakers and their fellow support group members.

Each person, patient or family member, is encouraged to tell their own story, all within a supportive environment, where we all recognise that each brain tumour journey is unique. The BTAA Sydney Support Group has truly become a family, where anyone, regardless of what part of the brain tumour journey they're on, is made to feel welcome.

Senate Committee Unique Opportunity For Improved Rare Cancer Outcomes



Alice Parsons, Philip Steel, Catherine Hindson, Trish Berman, Nicola Sheehan at the Senate Enquiry.

In 2016 the Senate established a Select Committee into Funding for Research into Cancers with Low Survival Rates to inquire and report on the impact of health research funding models on the availability of funding for research into cancers with low survival rates.

The closing date for submissions was 31 March 2017. Public Hearings were conducted on 8 June 2017 and 29 Aug 2017 in Canberra and 04 Aug 2017 in Melbourne. The BTAA made its submission on 8th of June along with private submissions from, Denis Strangman, Susan Pitt, and Billy Williams.

The Terms of Reference for the Inquiry included the impact of health research funding models on the availability of funding for research into cancers with low survival rates, which focused the current National Health and Medical Research Council funding model, and the obstacles to running clinical trials for brain cancers and other cancers with relatively lower rates of incidence given the low survival rate for brain cancers, lack of significant improvement in survival rates, and strategies that could be implemented to improve survival rates.

Anyone who is interested can view the many submissions to this inquiry, watch video of the evidence being given and view transcripts at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Funding_for_Research_into_Cancers/FundingResearchCancers

The committee is to inquire and report by 28 November 2017.

11th International Brain Tumour Awareness Week 2017

Sunday, 21 October to Saturday, 28 October 2017 inclusive. We encourage you to organise your own activity to mark the week. Bang on a beanie, Wear a Hat in Cup Week.

IBTA Week Melbourne Community Education Forum

Sunday 22 October 2017 : 1.30pm for 2.00pm start

Rydges Melbourne Hotel, 186 Exhibition Street, Melbourne,

Held in association with 10th COGNO Annual Scientific Meeting

This free forum is open to patients, carers, or anyone interested in learning more about brain cancer.

Come at 1:30pm, Session from 2pm to 4pm

See the program and book now here :

<http://www.btaa.org.au/events>

Speakers Include:

1. Professor Patrick Wen – Senior Neuro-oncologist
2. Dr Daniel Kelly – Neurosurgeon, John Wayne Cancer Institute
3. Dr Lawrence Cher – ONJ Cancer Centre
4. Professor Jennifer Philip - St Vincent's Hospital

Topics include:

1. Current Directions in Treatment – International & Local perspective
2. What's the Buzz – Medicinal Cannabis and Cancer

Supported by:

BTAA www.btaa.org.au

Olivia Newton-John Cancer Wellness and Research Centre

<http://www.onjcancercentre.org/>

COGNO www.cono.org.au



2017-2018 BTAA Committee

BTAA's AGM was held on
Sunday 24 September 2017.
The following were elected:

Executive members

Chairperson: Catherine Hindson

Vice chairperson: Philip Steel

Secretary: Trish Berman

Assistant Secretary: Susan Pitt

Treasurer: Pat Wynn

Ordinary Committee members

QLD Julia Robertson

NSW Alice Parsons

VIC Janet Micallef

ACT William Williams

NSW Pam Hubner

NSW Stephen Newman

VIC Rigoula Roussakis

Public Officer: Tricia Berman

Specialist Advisers: Denis Strangman, Matthew Pitt.

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

Support: Catherine Hindson

Inform: Philip Steel

Represent: Susan Pitt

Connect: Janet Micallef

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



Catherine Hindson



Philip Steel



Trish Berman



Susan Pitt



Pat Wynn



Julia Robertson



Alice Parsons



Janet Micallef



Stephen Newman



Rigoula Roussakis

Thank you for assisting us with our Cancer Australia project

By *Tricia Berman*

Cancer Australia's Supporting people with cancer Grant initiative aims to reduce the burden of cancer through the provision of grants to community organisations and to encourage effective partnerships between organisations.

BTAA was awarded funding from Cancer Australia in 2016 through a Supporting people with cancer Grant initiative.

The BTAA grant is to support people with a brain tumour, and their carers and family, through the provision of appropriate evidence-based information including linguistically accessible resources.

Two information resources have been identified by the Project Steering Committee and Team, and in September 2017, discussions were held with patients and carers in Sydney (September 1), Brisbane (September 16) and Melbourne (September 23) to obtain feedback on the proposed information resources.

BTAA would like to thank all those patients and carers who have participated in the Discussion Groups. The input from patients and carers is critical

to the development of appropriate evidence-based information. Each Discussion Group was for 90 minutes and managed by a facilitator so that careful and constructive advice could be given to those managing the BTAA Cancer Australia grant project.

Changes will now be made to the resources so that they better suit the needs of patients and carers.

The next stage of the project will be to obtain feedback from medical professionals including surgeons, neurologists and brain tumour care coordinators on the proposed new information resources for brain tumour patients. This will occur in the next couple of months.

In 2018, the project will develop further with design work and production of the new resources, followed by translation for culturally and linguistically diverse communities including Arabic, Greek, Chinese, Vietnamese and Easy English.

The project is due to conclude in 2019.

Fabulous Wagon Nationals For Brain Tumour Support

Wagon Nationals is a charity car show that has been established to raise money for Not for Profit organisations and this year they again have chosen BTAA as recipient.

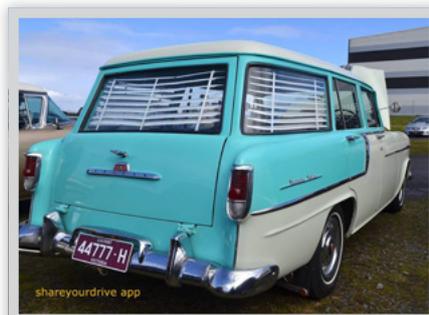
The Wagon Nationals attracts cars of all makes from all over Australia and provides a niche classic car 'show & shine' event for the owners of Wagons.

The event is organised by Lisa Chambers a brain tumour patient / survivor who chose BTAA as the delegated charity for this event as they helped her in her brain tumour journey and provided information resources to newly diagnosed patients and their families, including supporting the freecall number 1800 857 221 where you can speak to someone who knows what it is like to travel the Brain Tumour Journey.

This year there was a Charities Choice award and BTAA got to pick the car out of 200 cars on show. BTAA committee members Rigoula and Janet chose the winner (see picture of car and owner)

Last year, Lisa, her husband Darren and the National Wagon committee raised \$4500.00 for BTAA. This year they raised a generous amount of \$8,400.00.

We thank them for their continued support again.



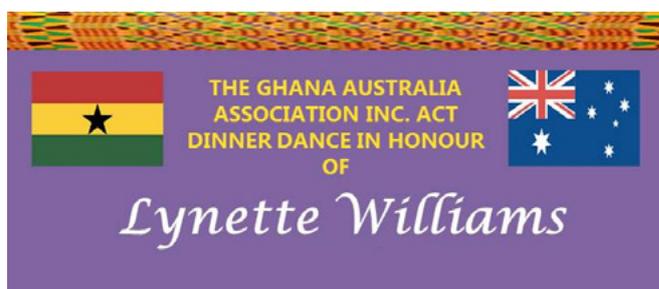
Dinner Dance to Honour Lynette Williams: 15 March 1954 – 14 April 2017

The Ghana – Australia Association will hold a dinner/dance in November to honour the life and service of Lynette Williams who passed away earlier this year from brain cancer. The event will raise awareness and support for two causes close to Lyn’s heart; the work of the BTAA, and an organisation in Ghana that supports children and adults with prosthetic arms and legs.

During a five-year period when Lyn and her husband Billy lived in Ghana, they became strong supporters of the Orthopedic Training Centre (OTC) as it reached out to those who were disadvantaged and discriminated against because of their disability.

It is because of this link and love for Ghana that the Ghana Australia Association will hold this event to honour Lynette’s life of service. To further Lyn’s legacy, Billy will return to Ghana next year for two months to do voluntary work at the OTC

The dinner/dance will have a distinctly Ghanaian flavour with drumming, dancing and the colourful dress that is strongly associated with the culture. The event is on 11 November at the Southern Cross Club, Philip, Woden. Tickets are \$85 and are available through the BTAA site. We do hope that many of you will be able to join us.



Amazing Peace of Mind Events

Geelong based organization, Peace of Mind Foundation, continues to provide an amazing array of events and services to support brain cancer patients and their families. The foundation is not research based, but seeks to provide financial, emotional and practical support to families that have to meet the demands of everyday responsibilities in times of crisis.

Besides promoting brain cancer awareness, Peace of Mind Foundation has three main areas that they are focused on:

- Counselling and Support
- Financial Aid
- In Home Support Services

The foundation has recently conducted a Men’s Retreat, a Women’s Retreat, Josies Ride for Brain Cancer, A 4WD day, and a Family Day Out, to only mention a small selection. They have also hosted a number of successful fund raising events as well.

Clinton Matthews and sister, Rebecca Picone are the driving force behind this passionate and committed organization. To find out more and keep up with upcoming events visit: <http://www.peaceofmindfoundation.org.au>

Peace of Mind - Women’s Retreat for Brain Cancer

The second Women’s Retreat for Brain Cancer will be held from 13 – 15 October 2017.

Rebecca Picone, the Director, has organised an exclusive weekend of pampering, friendship and indulgence for female brain tumour patients and carers at Peppers, The Sands Resort, Torquay, Victoria

Participants will enjoy 4.5 Star Resort Accommodation - Cocktail Dinner - Professional Individual Pampering - Wine & Cheese Tasting - Chocolate Factory Tour - Inspiring Guest Speakers

See more about the services provided at <http://www.peaceofmindfoundation.org.au/>

FUNDRAISING FOR BTAA

Lynsey Watson's Pin Up October

For the entire month of October members of the Australian Miss Pin Up world will be wearing pin-up and rockabilly attire in order to raise awareness for charities of their choices. Lynsey has chosen the BTAA as they have been a pivotal part of her life for the last two years as she has battled against brain tumours herself. The work of the BTAA has not only vastly improved Lynsey's life but continues to tirelessly do so for so many others living with brain tumours.

\$405 raised of \$1,000 Goal

For daily photos of Lynsey's pin up outfits and adventures, feel free to follow her on Instagram

www.instagram.com/ettienne_exhibition



Andrew Landers's Stretch's Shave for BTAA

In 2011, Andrew (affectionately known as Stretch) was diagnosed with an Oligodendroglioma. At the time, Stretch and his wife Kath, along with their almost 6 year old daughter Tahnee, had just moved into their first new home. They were also expecting their second child, with Kath only being 8 weeks pregnant with their son Harry. A trip to Chermshire Shopping Centre changed their lives forever when Stretch collapsed and was rushed to hospital. Within days he was undergoing major brain surgery. From this day forward, nothing would ever be the same. Stretch would like to give back to Brain Tumour Alliance Australia (BTAA) for the support they have provided to the family over the past 6 years.

\$4,068 raised of \$2,500 Goal

Horizon Credit Union Gets Behind BTAA

Staff from the Albion Park Horizon Credit Union ran a movie night fundraiser for Brain Tumour Alliance Australia and raised \$1300 which will go towards operating their 1800 phone number for the next 12 months. The 1800 number is used for brain cancer patients, their families and caregivers to connect with BTAA for help and support. Thank you, Albion Park, for organising a great event and to everyone who donated for their generosity and support!

Thanks to Anne, Michelle, Jo-Ellen (Branch Manager), and Melanie.



David Stratton's Celebration of Kerrie's life

\$2,640 raised of \$1,000 Goal



Donate or fundraise for BTAA

BTAA relies on the generous support of its fundraisers to help us increase awareness, and growing our community. There are many ways to fundraise for BTAA. You can set up your own fundraising page on the BTAA website, and share it with your friends, family or colleagues who may sponsor you in your fundraising efforts.

Read more here www.btaa.org.au/page/21/fund-for-btaa

MEMBER SPONSORSHIP AND EDUCATIONAL GRANTS



Susan Pitt, Sherryn Davies and Catherine Hindson at COGNO 2016

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.

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 \$ 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.

For more information on our grants and educational grants contact The Treasurer, c/- SHOUT, PO Box 717 Mawson, ACT, 2607 or through our website.

One of Educational Grants this year was to Sherryn Davies from the Queensland Cancer Council.

Sherryn's Report

As the Community Support Coordinator at Cancer Council Queensland responsible for the provision of Brain Tumour Support Service, I was very fortunate to receive a grant from Brain Tumour Alliance of Australia (BTAA). This grant supported me in attending the ASNO-COGNO Annual Scientific Meeting (ASM) as well as the BTAA Forum and AGM. At the ASM I was able to learn from world leaders in neuro-oncology, witness debates about which clinical trials should be supported and why, and network amongst peers. The advances in personalised medicine are exciting and the way of the future in terms of diagnosis and treatment. The lunch session on having difficult conversations was interesting and demonstrated how we as professionals can listen and respond appropriately to their concerns and emotions, and support the patient and their loved ones with care and empathy. The term "patient centred care" was used many times over the three days and was very heartening to hear.

The BTAA events also provided great information on the advances in personalised medicine, as well as having the opportunity to mix with and learn from patients and peers. We heard from international experts as well as representatives from Australia promoting the importance of peer support, and access to palliative care, not just for end of life, but also for symptom control, relief and support.

My attendance at these events provided me with an insight into high quality research, and support services and resources available, both nationally and internationally, and provided me with confidence that people with brain cancers can look forward to a brighter future.

Sherryn Davies

How To Donate

www.btaa.org.au/donations
(immediate receipt)

Direct Debit

BSB: 062 900
Account: 1060 3153
Email: btaa@shout.org.au for a tax receipt

Cheque

BTAA
P.O. Box 717
MAWSON ACT 2607

Nicola Scott Educational Grants Fundraising Event

The Nicola Scott Educational Grants provide funding for 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.

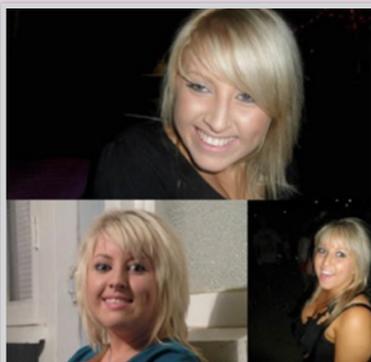
The Nicola Scott Educational Grants were set up in memory of Nicola Scott who passed away on 2 July 2012, 23 days short of her 21st birthday, after being diagnosed with a low grade (Oligodendroglioma) at 13 years of age. Nicola was the daughter and only child of Michael and Tracy Scott.

This year's fund raising event occurred after months of organising and sourcing items for raffles. The fundraiser was held on 8 July 2017, 4pm at Sandy Gallop Golf Club, Ipswich.

Master of Ceremonies for the event was Nevin Clifford, with a speech from then Acting Mayor Paul Tully, with guests from all over Qld and NSW. Generous donations were made from the Sandy Gallop Golf Club for the venue, ACC Higgins and James Frizelles Automotive Group and suppliers for our raffle items:

- Ipswich Jets Leagues Club
- Kent Papworth
- Wes Heritage
- Matt Scott North Queensland Cowboys
- David Dickenson and Rick Nelson
- Scott, Bayley, Bishop, Elder and Reick families
- Brisbane Roar FC
- QRL
- Qld Rugby Union
- Stefan
- Good Price Pharmacy Warehouse.

Huge thank you to those who bought raffle tickets, made it to the Fundraiser on Saturday and to those who have and are still donating to Nicola's BTAA Fundraising page online. An outstanding \$8,271 was raised at the Event alone.



Nicola Scott Educational Grants

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. 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 expenses may be available at the discretion of the BTAA committee.

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

For more information on our grants and educational grants contact
btaa@shout.org.au chair@btaa.org.au

Hannah's Story



Hannah (left) with sister in law Khadijah

Hannah contacted the BTAA on our help line recently during an extended hospitalisation following a stroke in an operation to remove a meningioma. She is still recovering with the support of her family and young children, but was very happy to contribute to our newsletter. Ed.

I am 35 and I have a meningioma. It's benign, so I guess I am lucky, but it's near my brain stem so the neurosurgeon said 'you've got the best tumour in the worst spot'.

In May, I had surgery to de-bulk it. I was told I had no real choice. It seemed to be growing and was pressing on nerves, blocking the fluid to the brain and was near the main artery. During the operation, I had a very rare complication, a brain stem stroke. So rather than having a 3 month recovery, I was to spend 3 months in hospital and thrown into the world of allied health!

I've still got a bit of the tumor left in my head. They got about 80% but had

to stop the operation when the stroke occurred. The tumour had captured the blood supply and you can't see all blood vessels on scans. Now it has no blood supply, let's hope it dies, but if it grows, the neurosurgeon said he'd recommend radiation.

All the symptoms that I had have gone. The vertigo I've had for years (which wasn't so benign after all), the tingling on my face and hands and the headaches I'd wake up with. But it was the recent, overwhelming fatigue that got me to check my head. I hadn't felt well for years and my symptoms were put down to anxiety. The CT scan I had two years ago came back negative, so I thought my head was fine. The problem is that the brain stem is a bit hard to see, although an MRI picked it up in April and they operated about three weeks later.

The neurosurgeon told me that this was a major surgery, as did the nurse who was there at pre-admission. They went through the risks but I

didn't think they'd happen to me. Waking up and not being able to move, talk or eat is pretty scary.

My tumor was on the left so I'm right side affected. As I was right side dominant I am madly getting the motor skills on my left side up to scratch. I typed this whole thing with my left hand.

The thing about the brain stem is it's like the reptilian part of your brain. No thinking is done there, so my thinking is fine, but it controls all your automatic functions, so it's quite important. When I came out of the operation, they told my family 'we don't know if she'll ever talk, eat or move her right side again'.

Thankfully I'm now doing all those things, albeit badly. But hopefully it improves. They just say they don't know. There are so many things they don't know about the brain. Which is both comforting and terrifying!

AIM BRAIN to Improve Targeted Treatments

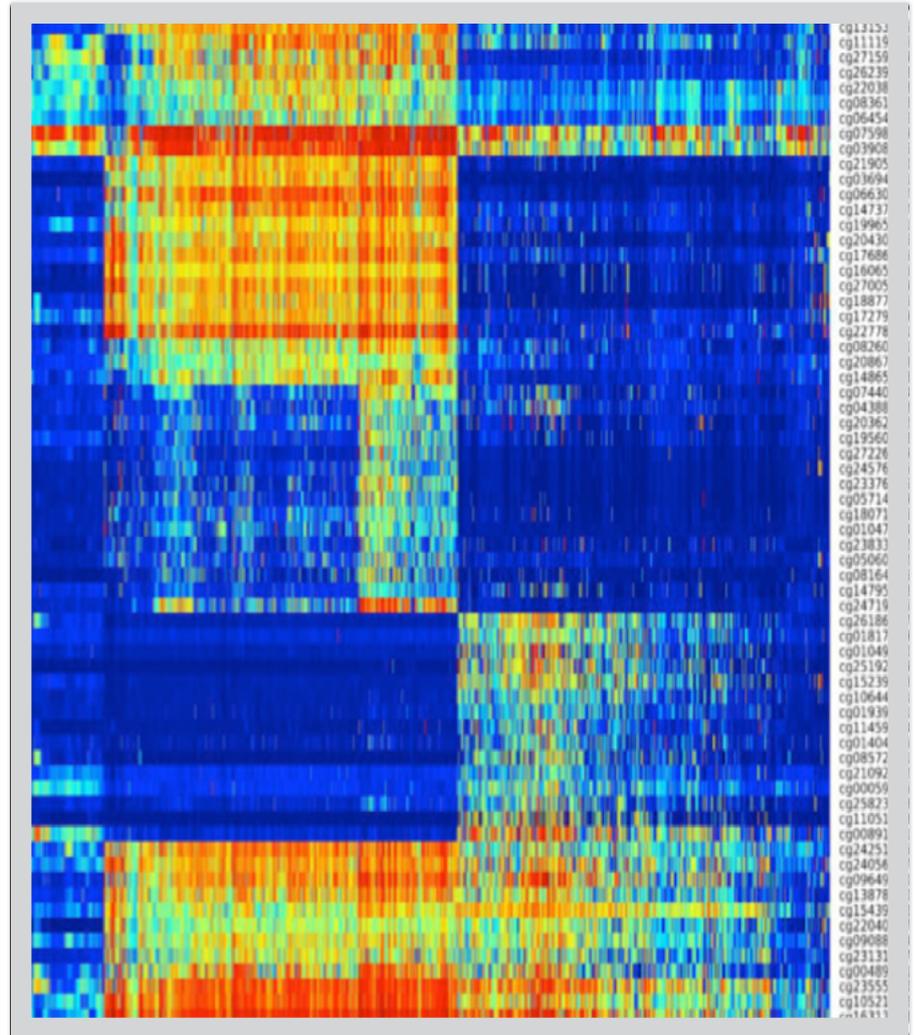
By Susan Pitt

Congratulations to the Robert Connor Dawes Foundation (RCDF) on the announcement in August 2017 by the Minister for Health, Greg Hunt, of the AIM BRAIN project.

They have committed \$1 million over four years to get the project up. The AIM BRAIN project helps doctors better understand individual types of tumours. With better understanding, treatments can be better tailored to the individual, brain tumour battlers increase their odds of beating the cancer and in some cases, not risk being over treated.

The project brings world-leading tech that helps doctors better understand and classify individual tumours. With a clearer understanding of each tumour, specialists can create better, personalised treatments not just based on the placement of a tumour but on its actual molecular build. The new approach will not only help them target treatments more appropriately but also reduce the likelihood of debilitating treatment side effects as more intensive treatments are reserved for the most aggressive tumours.

There are around 120 different types of brain tumours and each one responds differently to various types of treatment. In the past couple of years, there have been significant breakthroughs in the ways the specific tumours are identified through a process called 'methylation arrays' which analyses DNA. Essentially, this will give doctors more specific information about the type of tumour someone has, and they will be able to develop ways to tailor the treatment for the best possible outcomes.



**Clustering of brain tumours on a methylation "heat map".
Image from Columbia University Medical Centre**

Using state of the art technology, this research will examine the chemical tag, methylation, on the DNA of thousands of genes in brain tumour samples. Methylation tags are present in different patterns that are unique to different types of brain tumours. Hence these unique methylation patterns can be utilised to refine the diagnosis of a tumour thus ensuring that the most effective treatments are given.

Personalised diagnosis and medicine is at the very forefront of cancer treatment globally and was previously only available in the US, Germany, Canada and a small number of other countries. The project is an Australian-first RCD initiative in collaboration with ANZCHOG, The Australian and New Zealand Children's Haematology/Oncology Group.

Highlighting brain cancer research in bright red

A CLOSE circle of friends continues highlighting the need for brain cancer awareness in bright red. Vibrant red was their friend Sue Cornish's favourite colour.

The second annual Red Gala Ball continues to be a way they honour the memory of Sue, who died of an inoperable brain tumour two years ago.

Red Gala Ball raised almost \$20,000 this July, double their efforts of the inaugural ball.

They will again donate \$1500 to Brain Tumour Alliance Australia and the balance to Carrie Bickmore's Beanies for Brain Cancer.

A signature red cocktail helped boost the tally, with host venue Miners Tavern donating half the price of each cocktail to the cause. The cranberry and vodka punch was also one of Sue's favourite drinks.

Brain cancer kills more people aged under-40 than any other cancer. Incidence and mortality rates have showed little change over the last three decades, according to Beanies for Brain Cancer.

The Red Gala Ball seeks to continue to raise funds in support of Carrie Bickmore's "Carrie's Beanies 4 Brain Cancer" and "Brain Tumour Alliance Australia", in honour of our good friend Sue Cornish who passed away in 2015 after her battle with brain cancer. Congratulations to Mel Tempest and her wonderful team in Ballarat.



Close friends reunite in red in honour of good friend Sue Cornish, who died of a brain tumour two years ago. They raised almost \$20,000 for brain cancer support.

The 2017 International Brain Tumour Awareness Week

BTAA partners with the International Brain Tumour Alliance (IBTA) to keep our Australian subscribers well informed about all the developments in research, support and advocacy.

The IBTA lead the 11th International Brain Tumour Awareness Week, which will be held from Saturday, 21st October to Saturday, 28th October inclusive. We encourage you to organise an activity which will contribute to increased awareness about brain tumours. It could be a walk (see information about the Walk Around the World for Brain Tumours), a picnic, an information seminar, a scientific conference, or the distribution of a media statement to local media which draws attention to the particular challenges of a brain tumour and the need for a special response and an increased research effort.

Our Chair, Catherine Hindson, will be representing BTAA at the Third World Summit of Brain Tumour Patient Advocates in London.

Organisations and individuals taking part in The International Brain Tumour Awareness Week can download a logo to promote their activities.

BTAA Membership



It is easy to become a financial member of BTAA.

The application fee is \$20 and the annual membership fee is \$10, payable up to 10 years in advance.

www.btaa.org.au/page/23/become-a-member

Mel Goes Grey Again in May Again for 2017



Many members of the brain tumour community attended Mel Johnson's annual Mel Goes Grey In May event on 27th May in Bathurst.

It was another fabulous night as always, and was very well supported by the generous Bathurst community. Guest speakers included prominent neurosurgeon, Dr Brindha Shivalingam and Dr Kimberly Kaufman, a prominent researcher at the Chris O'Brien Lifehouse, RPA in Sydney. More than \$7,500 was raised which is a great tribute to Mel, a former brain tumour patient herself, and her family and support team.

Professor Buckland and Dr Kaufman receive a cheque for \$5000 from Mel



Molecular scientist, Dr Grace Wei, firing up the new deep sequencer. With the help of Brainstorm, RPA Neuropathology is rolling out 21st century genomics for brain tumour diagnosis and personalised medicine.



Dr Kim Kauffman, Catherine Hindson, and Dr Brindha Shivalingam with Mel Johnson.

Dainere's Bus Raises Awareness

Dainere's Rainbow Brain Tumour Research Fund recently commissioned a full graphic treatment for a Canberra bus to help raise awareness about brain tumours in the ACT. Local businesses Transit Graphics, Qcity Transit, CDC NSW, Transborder Express and Screenmakers combined to produce the striking bus. This initiative is one that will certainly lead to an increased awareness and knowledge in the community of Paediatric Brain Tumours.

www.facebook.com/daineresrainbow/



Women's Retreat for Brain Cancer

hosted by *Peace of Mind Foundation*

Peppers The Sands Resort,
2 Sands Boulevard, Torquay Victoria

PEPPERS
THE SANDS RESORT
TORQUAY

13th-15th
October 2017

An exclusive weekend of pampering, friendship and indulgence for brain tumour patients and carers

4.5 Star Resort Accommodation - Facilities - Individual Professional Pampering - Evening Cocktail Dinner - Wine & Cheese Tasting - Inspiring Guest Speakers - Great Ocean Road Chocolaterie Lunch

\$180 per person (all inclusive)

Be quick to book your place, limited to 60 women only!

Tickets can be purchased online at www.peaceofmindfoundation.org.au

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



SPREAD THE WORD!

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



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