



THE OFFICIAL BTAA NEWSLETTER

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK EDITION 2018

OCTOBER 2018 EDITION

BTAA.ORG.AU



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Brain Tumour
Alliance
Australia



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MELBOURNE BRAIN CANCER SYMPOSIUM 2018

"Finding a proactive approach to patient care"

The Melbourne Brain Cancer Symposium will be a wonderful opportunity to hear from a number of specialists in the brain cancer arena.

Professor Terri Armstrong: PhD, Advanced Practice Nurse, researcher and brain cancer specialist will present the keynote address: "Proactive vs Reactive:

Dr Lawrence Cher: Research developments and directions in brain cancer direct from COGNO.

Dianne Legge: Brain Tumour Support Coordinator, will discuss practical strategies on fatigue management in brain cancer.

This symposium is targeted for those nurses, allied health professional and doctors who come into contact with brain cancer patients and would like to understand more and hear about recent developments in care and treatment.

To register go to: [Eventbrite.com](https://www.eventbrite.com) and search for **Melbourne-brain-cancer-symposium-2018-tickets**

Date and Time

Friday 12th October 2018
2:00 pm – 5:00 pm AEDT

Location

Olivia Newton-John Cancer Wellness & Research Centre
Level 5, 145 Studley Road, Heidelberg, VIC 3084



SHAPING THE FUTURE OF COLLABORATIVE CARE FOR NEURO ONCOLOGY

Wednesday 10th October 2018 5 pm -8 pm
Meet the leaders in Neuro Oncology

A.Prof Mustafa Khasraw

Highlights of COGNO 2018

Prof Susan Chang

Quality of life issues faced by patients and their families

Dr Terri Armstrong

Senior Investigator of the "Patient Outcome Program" at the U.S. National Cancer Institute.

This event is suitable for Medical, Nursing and Allied Health interested in the care of Neuro Oncology patients

Book through the BTAA website or call 02 84253610

Location

Wallace Freeborn Lecture Theatre
Level 5, Kolling Building, Royal North Shore Hospital
Reserve Road, St Leonards, NSW 2607



2018 DIARY DATES IMPORTANT EVENTS

EVENT	WHERE	WHEN
Brain Tumour Forum	Cancer Council Queensland 553 Gregory Terrace Fortitude Valley Qld	Sunday, October 7, 2018 10am – 2:30pm
Shaping the Future of Collaborative Care for Neuro Oncology	Wallace Freeborn Lecture Theatre Level 5, Kolling Building Royal North Shore Hospital Reserve Road St Leonards NSW 2065	Wed 10th October 2018 5pm- 8 pm
Melbourne Brain Cancer Symposium 2018	Olivia Newton-John Cancer Wellness & Research Centre Level 5, 145 Studley Road Heidelberg, VIC 3084	Friday 12th October 2018. 2:00 pm – 5:00 pm AEDT
"A Little Bit" fund raiser	Coorpao Bowls Club Brisbane, QLD	Sat 13th October 2018 6.30 – 10.30 pm
White Pearl Ball	Hyatt Regency 161 Sussex Street, Sydney	10th November, 7pm
SNO (Society for Neuro-Oncology) 23 Annual Meeting and Educational Day	New Orleans, Louisiana	November 15-18 2018
ACT Trivia Night	Canberra Croatian Club	30 November 7.00-11.00 pm
Brain Cancer Action Month	Australia Wide	May 2019

PICK YOUR BRAIN
Trivia Night

TICKETS
\$25 SINGLE
\$225 TABLE OF 10



GROATIA DEAKIN
FOOTBALL CLUB
3 GROSE STREET
DEAKIN, ACT 2600

Friday November 30th 2018 7pm-11pm

COME ALONG AND HELP FUND-raise
FOR BRAIN TUMOR ALLIANCE AUSTRALIA

THERE WILL BE ENTERTAINMENT
TRIVIA / GAMES
SILENT AUCTION & LIVE AUCTION
AND A LUCKY DOOR PRIZE!!

NIBBLES PROVIDED
MEALS AND BEVERAGES WILL BE AVAILABLE TO PURCHASE



TICKETS AVAILABLE AT
www.bttaa.org.au/events/23/pick-your-brain-trivia-night



LETTER FROM THE CHAIR

International Brain Tumour awareness Week

The International Brain Tumour Awareness Week is held every year across the globe to raise awareness, and to raise funds for support and research. We produce this newsletter each year during International Brain Tumour Awareness Week to acknowledge the many groups, both small and large, and the individuals, that work tirelessly to improve outcomes for brain tumour patients, their carers and their families across Australia. This year, from Saturday 20 October to Saturday 27 October, people around the world will hold walks and activities to raise awareness and fund for support and research.

This year during International Brain Tumour Awareness Week the Cooperative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting will be held in Brisbane from the 7th to the 9th October. The Mark Hughes Foundation and Brain Tumour Alliance Australia are pleased to be sponsoring one of the speakers, Dr Terri Armstrong who is a senior investigator and leads the Outcomes Research Section in Neuro-Oncology Branch at the Centre for Cancer Research at the National Institute of Health in the United States of America.

Terri will also speaking at the Patient Forum at the Cancer Council Queensland in Brisbane on Sunday 7th October 2018. All readers are invited to register for this opportunity to hear from some of the world's experts on brain tumour treatment and care. Registration is available on the BTAA website and travel grants are available for patients who need to travel some distance to attend.

Following COGNO Dr Armstrong will also be speaking at educational sessions for the medical staff in both Sydney and Melbourne. Details of these events and registration are available within this newsletter. The Sydney meeting on Wednesday 10th October from 5.30 until 8pm, is called Shaping The Future Of Collaborative Care For Neuro Oncology and will be held in Wallace Freeborn Lecture Theatre Level 5, Kolling Building Royal North Shore Hospital. The Melbourne education meeting is on Friday 2pm until 5pm at the Olivia Newton-John Centre.

A new annual COGNO poster Award, the BTAA Lynette Williams Award, has been set up by BTAA Committee member Billy Williams in memory of his dear wife. The funds for this award were raised by the Ghana Australia Association. The COGNO Award is for posters from any discipline in research related to supportive care for people with brain tumours. Many thanks to Julia Robertson who assisted in its establishment.

Brain Cancer Action Week

The month of May was all about Brain Cancer Action activities. BTAA attended and supported Patient Forums in Sydney, Newcastle, Melbourne and Geelong. BTAA foresees that next year patient forums will be held in other states as well. All events were very well attended and many patients and their families travelled long distances to attend, demonstrating the ongoing need for this type of event.

The Sydney forum was organised by NSWNOG, the Newcastle by the Mark Hughes Foundation, the Melbourne forum was held at the Olivia Newton-John Cancer Centre and the Peace of Mind Forum conducted of forum in Geelong.

BTAA ambassador, Melissa Johnson also held her annual Mel Goes Grey in May dinner and fund raising night. Over \$10,000 was raised and this was shared between Royal Prince Alfred Brain Storm Research Centre and the BTAA. As usual, the evening was a lot of fun, and was well supported by local identities, doctors and researchers and members of the brain tumour community. Well done to Melissa and her team on another great effort.

Visit With Senator Bilyk

Last month Steve Newman and I were delighted to visit Senator Bilyk at Parliament House. Senator Billick chaired the Senate inquiry into Cancers with a low survival rate. Stephen and myself spoke about the need for more consistent support for brain tumour patients and carers.

Monthly E-News

A big thank you to one of our Sydney committee members, Steve Newman, Steve has taken over the task of delivering our e-news and is producing it monthly. We welcome articles and news items that you would like distributed to our subscribers. Contact enquiries@btaa.org.au

Support Groups

A Support group is being reformed on the Gold Coast in the near future. For more information contact enquiries@btaa.org.au. Meanwhile the BTAA Sydney Support group at the Lifehouse and the BTAA ACT Support Group continues with monthly support meetings. Thanks to the dedicated coordinators Alice Parsons, Steve Newman, Gerry Tye, Pat Wynn and Billy Williams. A training program is also underway in conjunction with the NSW Cancer Council to offer support leader training to support group leaders across the country.

(Continued on page 4)

(Continued from page 3)

It is hoped that this program will increase the coverage and effectiveness of support groups nation wide.

School Support

Two schools had fund raising activities recently, The Sunshine Beach State School in Queensland in memory of Adam Bruin. The other was inspired by a girl watching the publicity about the Beanies For Brain Cancer she wrote to her Principal at the Mother Teresa School in Canberra requesting they fundraise. They had a hot chocolate drink day.

As mentioned in previous newsletter a BTAA goal is that all people who are diagnosed with a brain tumour know where to access support and information. To achieve this we are seeking volunteers to help in all states to help distribute our brochures to Neuro wards, oncology and radiation units. If you wish to assist you can contact me chair@btaa.org.au

A huge thank you to Philip Steel Vice Chair for assisting me and also for producing this newsletter. Also a thank you to Pat Wynn our Treasurer for keeping our books perfect for the auditors.

Catherine Hindson
Chair BTAA Canberra



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

BTAA Promotes Support Groups

The BTAA is currently undertaking a training program to help train and develop support group leaders across the country. The program involves leaders, or future support group leaders travelling to training in Sydney provided by the NSW Cancer Council. During November 6 people will join in the one day program with more to follow in coming months.

Support Group Leaders. People will travel from as far as the Gold Coast to join in the September program.

It is hoped that the support leader training program will improve the coverage of support groups to all Australian capital cities and larger regional towns and cities. We want to ensure that all Australian brain tumour patients and their families have access to nearby support in the future. The program has been made possible by \$10,000 donated by the Tour de Cure, riding to Cure Cancer team and the training provided by the NSW Cancer Council.

If you are currently running a support group in your town or city, or are interested in forming a group, you should contact Catherine Hindson on 1800 857 221 to discuss training opportunities



BTAA Committee

Executive members

Chairperson: Catherine Hindson

Vice chairperson: Philip Steel

Secretary: Trish Berman

Assistant Secretary:
Billy Williams

Treasurer: Pat Wynn

Ordinary Committee members

NSW Alice Parsons

VIC Janet Micallef

ACT William Williams

QLD Pam Hubner

NSW Stephen Newman

NSW Michael Parsons

Public Officer: Tricia Berman

Specialist Advisers: Denis Strangman, Matthew Pitt.

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

Support: Catherine Hindson

Inform: Philip Steel

Represent: Susan Pitt

Connect: Janet Micallef

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

Brain Cancer Biobank Critical For Research

Lucie Leonard was 34 when she lost her seven-year battle with brain cancer in 2012. Her mother, Robyn Leonard, quickly became a passionate consumer advocate for brain cancer research and established a brain cancer biobanking consortium to network the fragmented collections of brain tumour tissue stored in biobanks Australia-wide.

She shared her story with the BTAA Support Group in Sydney in August.

"Biobanking is my passion. The tissue samples are donations from patients with brain cancer – it's such a precious gift, and I think it's really undervalued and I am on this mission to get support and funds for it".

Robyn established Brain Cancer Biobanking Australia (BCBA) in 2015 with a coalition of over 50 of Australia's leading brain cancer clinicians, researchers and biobankers. The team is dedicated to providing researchers with the tissue they need to make real breakthroughs in brain cancer research.

"It's critical to research, obviously no tissue, no research. But the situation in Australia when I looked at it was so fragmented – researchers didn't actually know where the tissue was," she said.

"So, my idea was – let's pull it all together and realise the value of all these individual donations, because

on their own none of the collections will ever have enough tissue to power the research that's going to make real breakthroughs".

BCBA brings together 18 biobanks across Australia in a virtual hub or network, giving researchers easy access to the amount, quality and type of tissue and associated data they need to accelerate both paediatric and adult brain cancer research.

In August, BCBA launched a dynamic, one-stop online shop to allow researchers globally to search and apply for brain cancer biospecimens available across the entire national BCBA network.

"We created the system so that researchers wouldn't have to contend with mountains of paperwork and time searching for tissues just to do their job".

BCBA is also working on a world-first minimum clinical dataset for brain cancer biobanking that will help standardise the data that is collected with the tissue within the network,

"There's no point having tissue without data, it's pretty much useless," she told the group in Sydney.

The consumer is always at the forefront of the BCBA activities, and the team are working on a rapid autopsy pilot project that will collect the brain of patients post-mortem, while the cells are still alive.

"The idea came from brain tumour patients wanting to donate their brain after they've died and coming to us and there was very little capacity around Australia to do this... I thought that's absolutely hopeless, we need to do something."

The project is cutting edge, and will allow researchers to grow cells in the lab and study how the tumour has been able to adapt and evade treatment.

"Being a consumer you can achieve a lot, there is no agenda. People get on board with you because it's all about the patients and research," she said.

In addition to small charitable and philanthropic grants, the not-for-profit group is supported by an annual Bike Ride for Brain Cancer. The group raised \$200,000 through the two-day 250km ride from Hornsby in Sydney to the Hunter Valley in March and will take to the road again in 2019.

"The ride happens each year on my daughters birthday, this is her legacy".

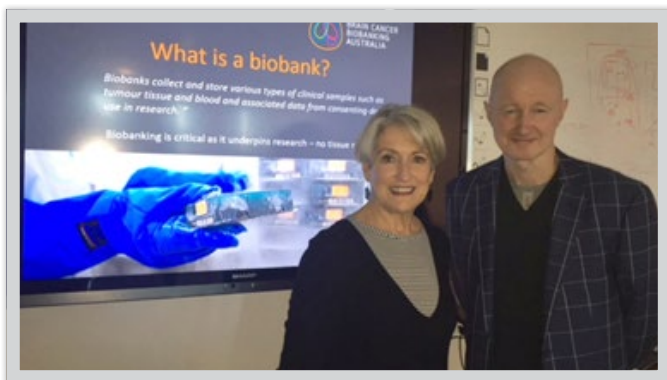
Register to take part in the 2019

Bike Ride for Brain Cancer:

www.bikerideforbraincancer.com.au/

To learn more about the BCBA:

www.bcba.org.au



Robyn with Lifeshouse Support Group leader Stephen Newman after speaking to members of the Sydney Group

Lucie Leonard was 34 when she lost her seven year battle with a grade 3 astrocytoma in 2012. Her mother Robyn Leonard quickly became a passionate consumer advocate for brain cancer research and was inspired to create Australia's first brain cancer biobanking consortium by the work of consumer advocates in the USA. Her vision was shared by leading brain cancer clinicians, researchers and biobankers across the country, who joined her pursuit to expedite researchers' access to tissue samples and data by networking and harmonising the disparate brain cancer biobanking operations Australia-wide.

Peace of Mind Provides Here and Now Support

Peace of Mind Foundation was founded in 2013 by Bec Picone and Clint Matthews, brother and sister, after Clint lost his wife Caroline the day of her 32nd birthday. The foundation is made up of a small group of passionate volunteers and professionals whose primary focus is to provide 'here and now' support to patients, carers and families affected by brain cancer.

The organisation is based in Geelong, Victoria and runs a brain tumour support group, offers funded counselling and financial aid for affected families and a small range of in home services to help alleviate day to day stresses. Nevertheless, Peace of Mind Foundation has become most well-known for its social days and incredible retreat weekends that it runs every year; a Family Retreat, and a Women's Retreat.

Founder/CEO, Bec Picone made the decision to start running these retreats after recognising the isolation that a brain cancer diagnosis can have on families. Launching an annual event that brings brain cancer affected families together from all over Australia was a way of helping support families in their greatest time of need and help bridge that gap within the brain cancer community.

Since its formation the organisation has provided financial support to over 60 Victorian families and connected over 200 families from all over Australia through its Retreats. Recently due to some grant funding from the Victorian State Government, Peace of Mind has been able to open back up their services to families all across Victoria, and their retreat weekends welcome guests from every state in Australia. We can provide support in the following areas, and encourage any brain tumour affected families living in Victoria



to contact us to see how Peace of Mind may be of assistance.

- Information and referrals
- Phone support, Support groups, social days and retreat weekends
- Funded In home practical support (gardening, house cleaning, transport)
- Funded Counselling
- Wish Grants (small financial aid for emergency expenses or end of life wishes)

In April 2018, Peace of Mind hosted its 2nd Family Retreat for Brain Cancer and had 100 people of all ages join them for a weekend of adventure, fun and friendship. Coming up soon in October will be time again for Women's Retreat 2018. An already sold out event! 60 ladies from across Australia will be pampered, inspired and spoilt rotten as they arrive on the 19th of October at the lovely 'Waurin Ponds Estate' in Geelong.

Peace of Mind is looking forward to increasing their reach within the brain cancer community and providing hundreds more families the opportunity to be part of their memorable retreats and to access their services. As well all know the brain cancer journey is challenging and life changing, so having people who truly understand is a real blessing.

To remain up to date with all Peace of Mind events and services please 'follow' us on Facebook

www.facebook.com/Peaceofmindfoundationaustralia/

and visit our website

www.peaceofmindfoundation.org.au

To donate, volunteer or find out more info please call Bec Picone on 0411 382 457 or bec@peaceofmindfoundation.org.au



National and International leaders in Research, Treatment and Care Gather at GOGNO

National and International leaders in Research, Treatment and Care Gather at GOGNO

Established in 2007, COGNO (Cooperative Trials Group for Neuro-Oncology) is a network of clinicians, researchers, consumer representatives and allied health professionals who are dedicated to increasing awareness, and improving treatment and end-of-life care for patients with brain tumours. The network currently includes over 650 health professionals and consumers from Australia, New Zealand and other countries. A principal role of COGNO is the development, conduct and support of innovative multi-centred brain tumour clinical trials in Australia.

The 2018 Annual Scientific Meeting (ASM) will be held in Brisbane, Australia from 7th-9th October. This year the BTAA and the Mark Hughes Foundation will co-sponsorship international guest speaker, **Dr Terri Armstrong**,



a senior investigator with the Neuro-Oncology Branch of the National Cancer Institute.

The BTAA has initiated an annual poster award in memory of **Lynette Williams**, for a poster from any discipline in research related to supportive care for people with brain cancers. The inaugural BTAA Lynette Williams Award will be presented during the Conference Dinner at the COGNO ASM.

ASM Convenor, Dr Mark Pinkham, and the organising committee have developed a vital and topical scientific program with the theme of 'Targeting survival: living well with brain cancer in the era of precision treatments'. Additional international guest speakers are:



- **Professor Susan Chang** – an internationally recognised leader in the field of neurological malignancies, Professor Chang specialises in the treatment of adults with brain tumours including glioblastomas and meningiomas. She is Director of the UCSF Division of Neuro-Oncology as well as Director of the UCSF Neuro-Oncology Gordon Murray Care Giver Program and Co-Director of the Sheri Sobrato Brisson Brain Cancer Survivorship Program.



- **Associate Professor Erik Sulman** – a radiation oncologist focused exclusively on the treatment of patients with brain tumours and internationally recognised for his biomarker efforts, A/Prof Sulman is Chief of the CNS/Pediatrics Section at the University of Texas MD Anderson Cancer Center.



- **Professor Mark Gilbert** – whose research interests centre on developing new treatment strategies for patients with malignant primary brain tumours. Professor Gilbert is Chief and Senior Investigator of the Neuro-Oncology Branch, National Cancer Institute.

Further details available on www.cogno.org.au

COGNO is committed to its engagement with the community and has formal involvement of people who have lived the experience of brain cancer, forming the COGNO Consumer Advisory Panel (CAP). Our CAP team have active engagement in COGNO activities, mainly through clinical trial development and review and will be in attendance at the ASM in Brisbane. COGNO is grateful to BTAA for the opportunity to share vital brain cancer scientific and medical research information presented at the ASM to the BTAA community after the Brisbane Conference, with contribution to a future BTAA newsletter from a CAP team member.

We have been hearing about much activity since the Australian Government announced its commitment to pledge \$50 million to the Australia Brain Cancer Mission through a Medical Research Future Fund in late 2017 and COGNO will share what this means for Australians with brain cancer, now and in the future in a coming edition – so watch this space...

Facebook Brain Tumour Support Group Success

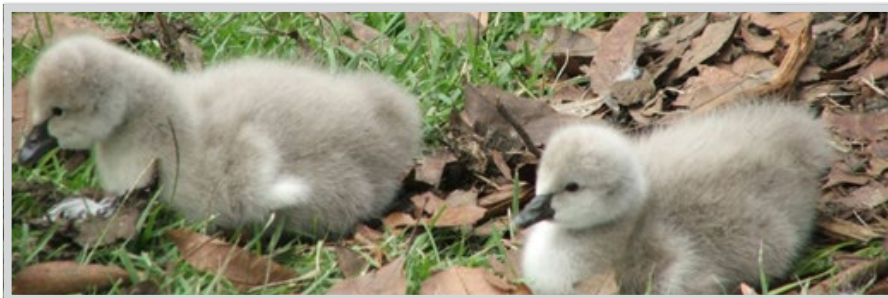
Brain Tumour Support Group Australia was born out of the need to connect with other patients, carers and families going through the impact of a brain tumour. No one understands the impact quite the same as those who are also “walking in the same shoes”. The group was created by Pauline Waring, whose husband has left temporal Oligodendroglioma diagnosed in December 2010 while having 4 children ranging in age from 8 to 12.

The group is a closed group and was opened for membership in December 2013, and has now grown to over 1000 members with over 990 active members.

A closed group means that only those people who are members of the group can see the posts made within the group and these will be visible to members only in their news feeds.

Membership is open to those with a brain tumour in Australia, or those caring for someone with a brain tumour, or with a family member or very close friend with a brain tumour or those who have lost someone close to them because of a brain tumour.

Members come from all over Australia. We do have a small number of members outside of Australia such as New Zealand, UK and US, including Australians who have gone overseas for treatment or to be with family members.



Top cities for membership are:

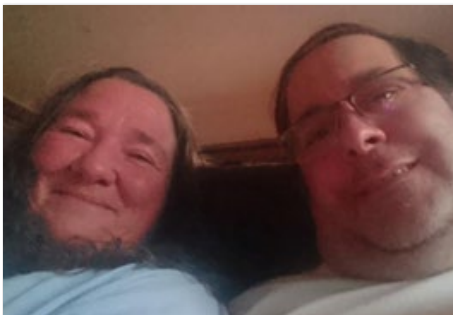
Melbourne, Victoria	203
Sydney, New South Wales	167
Brisbane, Queensland	94
Perth, Western Australia	59
Adelaide, South Australia	53
Canberra, Australian Capital Territory	29
Gold Coast, Queensland	28
Newcastle, New South Wales	18
Wollongong, New South Wales	14
Geelong, Victoria	13

The group is a very supportive caring group. We have many members from regional areas who travel to major cities for treatment and reviews. Members are advised to always seek the advice of their own care teams as every brain tumour is individual and every patient even if they have the same tumour as someone else in the same location, may have very different treatment needs or co-existing complications.

Between August 12 and August 18 2018 there have been 32 posts by members with 565 comments and 1,068 reactions and 8 new members have joined the group.

From the original group new groups have grown administrated by members of Brain Tumour Support Group Australia. These include:

- Brain Tumour Carers Support Group Australia open only to those caring for someone with a brain tumour in Australia now or in the past.
- Warrior Space Brain Tumour Support Group Australia open only to those with a brain tumour apart from the group administrator who is a carer.
- Australian Paediatric Brain Tumour Support Group open only to those caring or having cared for a paediatric child with a brain tumour in Australia.
- Brain Tumour Bereavement Support Group Australia open to those who have lost someone to a brain tumour in Australia.



Pauline's husband Scott was diagnosed with an oligodendroglioma just before Christmas in 2010. As they travelled between home and radiotherapy they often stopped in Alford Park in Gympie and during this time were able to watch these cygnets hatch and grow into swans. Checking on the welfare of the swans and feeding the ducks was a highlight in what was often a worrying and stressful time."



Cure Brain Cancer Foundation's dedicated volunteers at Walk4BrainCancer

Cure Brain Cancer Foundation Makes \$20 Million Commitment to ABCM Roadmap

The launch of the Australian Brain Cancer Mission (ABCM) in October last year, was the culmination of four years of dedicated work by Cure Brain Cancer Foundation to achieve greater focus and funding for brain cancer from the Australian Government. The Foundation was aided in its efforts by passionate ambassadors such as Dustin Perry and Senator Catryna Bilyk.

This ten-year, \$100 million strategic roadmap to double brain cancer survival and improve patients' quality of life was built on the back of increased awareness, 'one voice' communication - with a dedicated focus on children, targeted and persistent advocacy, and the tireless efforts of people impacted by brain cancer, some of whom are sadly no longer with us.

The ABCM brings together Government, philanthropists, and brain cancer organisations under a common research strategy, increasing the Australian brain cancer research funding pool (through the \$55 million Government commitment) and stimulating increased collaboration across states and territories.

Since October last year, Cure Brain Cancer Foundation has committed more than \$3.3 million to world-

class projects strategically aligned with the both the ABCM and its own mission: to increase brain cancer survival to 50% by 2023. This significant investment forms part of the Foundation's \$20 million commitment to the ABCM over the next decade, for which we are now fundraising.

As part of our ABCM commitment, the Foundation has funded two new Infrastructure Grants to grow critical capacity in Australian brain cancer research and three Innovation Grants to bring novel, creative ideas into the field of brain cancer. It also jointly funded (with Isabella & Marcus Foundation), the first adaptive clinical trial for children with DIPG, called BIOMEDE, giving these children new treatment options in Australia.

In July this year, the Australian Government announced further funding for Zero Childhood Cancer, a nationwide personalised medicine program run by the Children's Cancer Institute and Sydney Children's Hospital. This additional funding, provided as part of the ABCM, created a targeted brain cancer arm for the national clinical trial: Zero Childhood Brain Cancer, for which Cure Brain Cancer Foundation provided \$1.4 million seed funding for the pilot.

Other organisations have also joined the ABCM this year. We welcome the significant investments made by *Carrie's Beanies For Brain Cancer*, *Mark Hughes Foundation* and the *Children's Hospital Foundation*. There are still significant funds to be raised, but these investments mean the long road to a cure will now hopefully be shorter.

The next stage of the ABCM is now taking shape. We need to ensure that the right projects are funded, and that they are funded quickly and efficiently.

With no meaningful increase in brain cancer survival in more than 30 years, this is the best opportunity we have ever had to change the world for people living with brain cancer. While the funding will undoubtedly help, the reality is that it is not nearly enough. Now more than ever, we need the community to continue to fundraise, volunteer and advocate for change.

Former Health Minister, Greg Hunt, Cure Brain Cancer Foundation CEO, Michelle Stewart, Andrew Forrest, Cure Brain Cancer Foundation Head of Engagement, Barrie Littlefield at the launch of the Australian Brain Cancer Mission



New resources for brain tumour patients

Tricia Burman

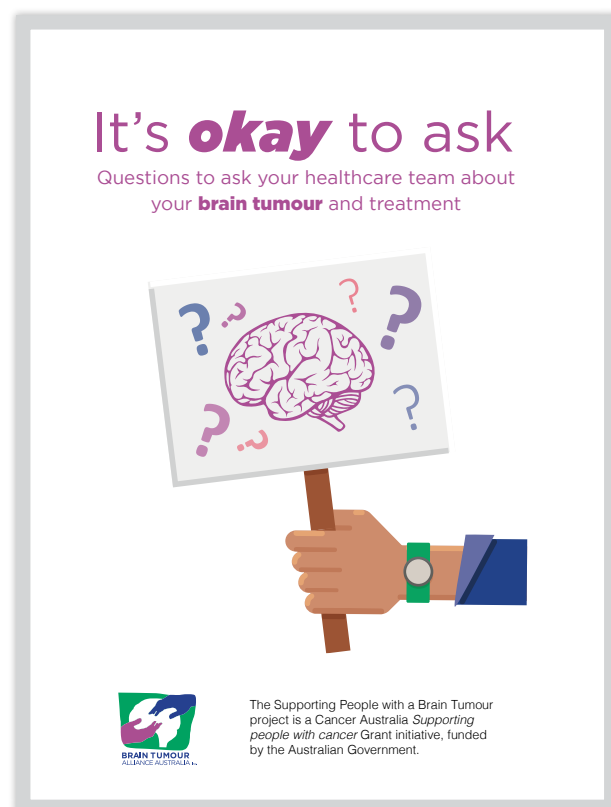
BTAA will shortly be releasing two new resources for brain tumour patients. The new resources will assist all newly diagnosed brain tumour patients to ask their health team questions about what to expect as they move along the treatment journey. Importantly, the new resources will be available in a range of languages so that every patient can use them. This is the first time that BTAA has produced brain tumour resources in different languages and we are pleased to assist a wider range of cultures to understand the brain tumour journey.

One resource is called 'It's Okay to Ask'. It is a short booklet of 36 pages that sets out questions for patients to consider in approaching their treatment. The questions are grouped under the following headings: Diagnosis, What to expect, Symptoms and Changes, the Healthcare Team, Support, Treatment and Management, and After Treatment.

The second resource is called 'Your Brain Tumour Pathway'. It shows in a diagram the various steps of the brain tumour journey including diagnosis and treatment. Also, it is quite unique as it provides patients with a profile of, and contact information specific to their particular brain tumour. The intention is that this document can be completed when the patient visits their surgeon and/or other medical professional after diagnosis. The resource will be available in over 10 languages to enable all patients irrespective of their cultural background to have their own brain tumour profile and treatment in hard copy.

BTAA will be advising the date of launch of the two new resources in the next few months. Our regular E-News will circulate details of the launch.

BTAA would like to thank Cancer Australia for its help in producing these two resources. The Supporting People with a Brain Tumour project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government.



Tricia is a retired senior public servant and brings a wealth of knowledge and skills to the BTAA. She started volunteering for the BTAA through her connections with other BTAA members. In the times she is not working for the BTAA, she loves to paint and travel, and enjoys entertaining family and friends. Tricia would like to ensure that all brain tumour patients and carers have access to the support and information they need across Australia.

Brain Tumour Forum - 7th October 2018

Brain Tumour Alliance Australia and Cancer Council Queensland invites you to attend a free forum for people diagnosed with brain tumour and their families and friends. During this event participants will have the opportunity to gain information and guidance on living well with the diagnosis, as well as share experiences in a safe and supportive group environment.

Topics include:

- Be your own best advocate
- Latest in treatment for brain tumours
- Exercise as medicine
- Managing cognitive deficits and fatigue
- Patient and carer group sessions

When: Sunday, October 7, 2018

Time: 10am – 2:30pm

Where: Cancer Council Queensland
553 Gregory Terrace, Fortitude Valley

For full details and to book your seat, visit the BTAA webpage at btaa.org.au

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

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

The carer education and support program includes a telephone assessment of the carer's needs, a nurse home visit, a personalised printed resource file tailored to the specific needs of that carer and patient, and ongoing telephone support for 12 months. Some examples of carers needs include encouraging them to care for themselves (mental and physical health); help communicating with doctors; help understanding treatment; information on understanding physical symptoms;

understanding mental and behaviour changes; making choices on fertility and sexuality; lifestyle choices such as diet, exercise and complementary medicines, and end of life care. When the nurse identifies these unmet needs, he or she can give extra information, support, education and refer to someone else who can help in more depth, if needed. Because things can change quickly when caring for someone with high grade glioma, the nurse calls each month to check in on new concerns and is also available for ongoing phone support.

Although it seems obvious that extra support will help carers, to persuade Medicare and health services to include this type of program as routine, we need to also prove that it helps. The only way to do this is to compare two groups of similar carers, who do or do not receive the extra support. To understand whether the carer support program truly makes a difference to carers, half the carers who participate in the study are randomly assigned to have contact with the 'carer nurse'

and receive the extra support and education package, and the other half will continue to receive the usual support and education which is available through the patient's treatment centre. Both groups of carers fill in questionnaires so that we can understand and compare their quality of life and emotional health. Healthcare systems will also want to understand whether extra support in the short term reduces healthcare costs in the long term – for example, by reducing hospital admissions through supporting carers better. This study is also looking in detail at the economic costs and savings of the support package, which is why we are asking people in the study to keep track of healthcare costs, hospital visits, and allied health visits.

To date, 126 participants from WA and 20 from NSW have joined the study and are helping to answer this important question. We are keen to recruit more participants in WA and NSW and welcome enquiries about the study via email: g.halkett@curtin.edu.au.

Study Participation for Caregivers



The purpose of this study is to find out if educational material and nursing support may improve the experience of caring for someone with an aggressive brain tumour (high grade glioma).

If you are a caregiver of someone with a HGG who is undergoing treatment and are interested in finding out more information about the study please contact

A/Prof Georgia Halkett: g.halkett@curtin.edu.au

NSW Research Nurse Robyn Attwood: 0490 432 025 or email:

Robyn.Attwood@uts.edu.au

WA Research Nurse Jenny Clarke: 0401 103 578 or email: j.clarke@curtin.edu.au

Research roundup from the International Brain Tumour News

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

Clinical trial of nivolumab immunotherapy in elderly glioblastoma patients underway in Australia

A randomised phase 2 clinical trial of the immunotherapy agent nivolumab in combination with standard temozolomide chemotherapy, compared to temozolomide alone, in elderly (65 years+) glioblastoma patients has commenced at the NHMRC Clinical Trials Centre in Sydney, Australia. The trial, also known as NUTMEG (Nivolumab and TeMozolomide vs Temozolomide alone in newly diagnosed elderly patients with Glioblastoma), aims to recruit 102 patients across up to 18 sites in Australia and the study may be extended into a larger phase 3 trial, depending on results. Visit the COGNO website for further information on this and other trials being coordinated in this area.

Epigenetic analysis of glioblastoma may predict outcome and aid precision medicine, study finds

A research group at the CeMM Research Center for Molecular Medicine of the Austrian Academy of Sciences, analysed epigenetic markers (DNA methylation) in more than 200 glioblastoma patients, focusing on the changes that occur during glioblastoma disease progression.

Combination immunotherapy shrinks melanoma brain metastases, phase 2 study concludes

Results from a phase 2 clinical trial of the checkpoint inhibitors ipilimumab and nivolumab in patients with melanoma skin cancer that had spread to the brain found that the therapy had “clinically meaningful” effects.

Large collection of brain tumour data now freely accessible to researchers worldwide

A database of brain tumour biomedical data (the “Rembrandt” brain cancer dataset), which contains information on 671 adult patients collected from 14 contributing institutions from 2004-2006, has been made freely available to researchers worldwide.

Large study finds no link between exposure to high-frequency electromagnetic fields at work and brain tumours

A large multinational epidemiological study has found no association between occupational electromagnetic field (EMF) exposure and glioma or meningioma diagnosis, according to results published in the journal Environment International.

Study finds that brain tumours in children with neurofibromatosis 1 are more common than previously thought

Using new radiologic criteria, a study of the brain MRI scans of children diagnosed with the common genetic syndrome neurofibromatosis type 1 (NF1) revealed a frequency of brain tumours considerably higher than previous estimates.

Study identifies that ‘missing’ T-cells in glioblastoma patients are within bone marrow

Study gives direct evidence for the origin of glioblastoma tumours

A research team from South Korea has published evidence in the journal Nature describing how brain stem cells mutate to cause recurrent glioblastoma.

Researchers develop drug-carrying microparticle treatment to target IDH1/2 mutated gliomas

First FDA-approved trial of focused ultrasound to open blood-brain barrier announced

PET scan radiotracer uptake in glioblastoma may predict survival, study finds

Clinical trial results of engineered poliovirus for glioblastoma:

Studies links radiation therapy in paediatric brain tumours to impaired memory formation and hormone deficiencies

Genetically engineered ‘mini-brains’ developed to simulate brain tumour formation

Phase 3 trial of Tocagen’s Toca 511 & Toca FC in recurrent high grade glioma to continue without modification after interim analysis

Phase 1 trial of Moleculin’s WP1066 in glioma and brain metastases opens for enrolment

AIVITA Biomedical announces initiation of the first clinical site for ROOT OF CANCER glioblastoma trial

Forums Mark Brain Cancer Action Month

Susan Pitt

May was Brain Cancer Action Month and this was marked by forums in Geelong, Newcastle, Melbourne and Sydney. Organisations such as the Brain Cancer Group (Formerly NSW Society for Neuro Oncology), The Cancer Institute of NSW, Cancer Council NSW, Cure Brain Cancer, and the BTAA in Sydney, The Mark Hughes Foundation in Newcastle, Peace of Mind Foundation in Geelong, and the Olivia Newton John Wellness and Research Centre in Melbourne worked to organise these important events.

Each forum organised research leaders and local doctors and medical professionals to give presentations and take questions about important advances in treatment and care, as well as some more straight forward information for the newly diagnosed. All forums were well attended showing the continued demand for these types of events. A number of families received BTAA travel grants to allow them to travel to the Sydney and Melbourne events.

At the Mark Hughes Newcastle Forum which I attended, more than 100 patients and families had travelled from across the North East of NSW, from as far as Inverell in the West and Coffs Harbour in the North to hear the excellent speakers at the event. Interest was particularly high in gaining admission to clinical trials in rural and remote locations.

The Sydney Forum was also well attended and was led by Dr Johnathon Parkinson and Dr Elizabeth Hovey, who once again took time out from their busy schedules to support the event. Speakers and panellists included Dr Jacob Fairhall, Dr Eng-Siew Koh, A/Prof Helen Wheeler, A/Prof Kerrie McDonald and Dr Michael Rodriguez. After a lunch the focus was on support. Speakers included

Dawn Hutley, Catherine Hindson, Marina Kastelan, Kim Pearce, Prof Andrew Cole and Jo Marx.

The Melbourne Forum was held at the Olivia Newton John Cancer Wellness and Research Centre in Heidelberg, where the focus was again on new developments in Brain Cancer Clinical Trials, National Disability Insurance Scheme access and support and ways of living with brain cancer. Many thanks to Dianne Legge, the Brain Tumour Support Coordinator at the ONJ Centre for organising yet another fantastic event.

The Peace of Mind Geelong event focused on developments in personalised brain cancer treatment and research, the practical challenges of cancer, such as returning to work, travel insurance and accessing early superannuation, palliative care and personal stories from patients and carers. Another great effort by Bec Picone and the Peace of Mind team.



BTAA Chair Catherine Hindson, Dr Johnathon Parkinson and Dr Michael Rodriguez at the Sydney Brain Cancer Action Month Forum



Mark Hughes, Kiralee Hughes and Catherine Hindson at the Newcastle Forum



BTAA Committee members, Stephen Newman, Alice Parsons, Catherine Hindson and Philip Steel, at the launch of The Brain Cancer Group



Dr Liz Hovey, always passionate about brain tumour treatment.



Susan Pitt is a founding member of the BTAA and looks after the "Represent" area of the organisation. Susan's wealth of experience and tireless efforts in the brain tumour world since her son Matt was diagnosed with a brain tumour in 2009 has been a mainstay of the BTAA. Susan is also active in other cancer organisations and can be found at the helm of the Dragons Abreast dragonboat team at weekends

Grant Supports Neuro Oncology Nurse Practitioner

Pat Wynn

Transitional Neuro Oncology Nurse Practitioner at the Royal North Shore and Royal North Shore Private hospital. Marina Kastelan was recently supported by the BTAA Travel Grants Program to attend the Australian Neuroscience Nurses Association conference on the Gold Coast.

Marina educates, supports and assists patients and carers through the confusing pathway of brain tumour management. She works closely with members of The Brain Cancer Group (formerly SNOG) in post-operative co-ordination and assessment of newly diagnosed and recurrent primary brain tumour patients and adjuvant management of primary brain tumour patients with ongoing post discharge and outpatient support. Marina also provides additional holistic community support with over-the-phone assessment and triage is also attended.

Nurses, researchers and other health professionals can apply for travel grants under our educational grant program. Guidelines can be downloaded from our website.



Marina Kastelan at the ANNA Conference



Pat joined the BTAA after looking for support for her husband after he had his third brain tumour. She discovered the BTAA website and started attending the Canberra Support group. Pat's experience in book keeping and accountancy helps manage the finances of the BTAA. Pat loves spending time with her grandchildren and hopes to represent the BTAA at conferences to ensure that the BTAA gets the recognition it needs to be able to support those in need.

BTAA Member Sponsorship & Educational Grants

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 - Visit: www.btaa.org.au
Email btaa@shout.org.au
cc Catherine@hindson.org.au

Donations - Thank You

Sharon Leigh-Hazel, John & Raechael Thorpe, Helen and Barry Walls, Peter Scott, Michael Scott, Harriet Brown

Mel Johnson and "Mel Goes Grey in May"

The **Sunshine Beach State School** in Queensland in memory of **Adam Bruin**. The other was inspired by a girl watching the publicity about the beanies for cancer she wrote to her Principal at the **Mother Teresa School ACT** requesting they fundraise. They had a hot chocolate drink day.

Norman Disney

Vivien Deed

TKW Health

Members Meet With Senator Bilyk

Committee members Stephen Newman and Catherine Hindson recently met with Senator Catryna Bilyk to promote the need for support for brain tumour patients, carers and families. Senator Bilyk has been a long time supporter and advocate for the brain tumour community and was the chair of last year's Senate Select Committee 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.



Stephen Newman, Senator Bilyk and Catherine Hindson at Parliament House

Senator Bilyk is also a brain tumour survivor herself and her experience with brain tumours has motivated her to raise funds for research to improve the survival rate for cancer. To date, events she has organised have raised over \$120,000 for Cure Brain Cancer Foundation.

Senator Bilyk wrote on her Facebook page after the meeting:

"It was a pleasure to meet with Stephen Newman and Catherine Hindson of the Brain Tumour Alliance Australia (BTAA) Committee.

Catherine is the Chair of BTAA, and it was lovely to catch up with her again.

Stephen is overseeing the development of a new BTAA website, with the aim of improving BTAA's engagement with the brain tumour community. He has had a brain tumour himself, and is committed to the cause.

I'm delighted that he presented me with a copy of his novel, Collision, as well as sharing with me his ideas about further support for people who have survived brain tumours.

Keeping in touch with people who are working to help their community is one of the most rewarding aspects of my work as a senator."

Mel Goes Grey Success

Alice Parsons



Steve Semmens, Melissa Johnson, Sharyn Semmens and Stephen Harper at Bathurst RSL Club.

Bathurst brain tumour survivor and fund raising power house, Mel Johnson has once again hosted a fabulous "Mel Goes Grey" dinner. The event, held at the Bathurst RSL, was very popular and received great support from the local business community. Mel says that the aim for the dinners is to raise awareness and to raise funds for much needed research, as well as being a celebration of life. This year over \$10,000 was raised. Funds are used to support The Royal Prince Alfred Brainstorm research centre and the BTAA.

Well done to Mel and her dedicated team of supporters for their outstanding work in the brain tumour community.



Dr Michael Buckland and Dr Kimberly Kaufman from RPA Brainstorm sign a laboratory coat for auction.



Alice's thirty year old son was recently diagnosed with a brain tumour. Alice is a wife, mother of four, author, editor, troubleshooter, chauffer, custodian of bees and chickens, dog walker and bookworm. Alice hopes that through her participation in the BTAA she can contribute empathy and positivity to those on the brain tumour journey.

Committee member, Alice Parsons speaks at Mel's event

What's in that TASTY TREAT?
The 5 minute 'MAKE IT' comp
WHO or WHAT AM I?
BINGO
Lots of TRIVIA WHOO HOO!!
PRIZES
SILENT AUCTION
ROCKWIZ Style Music Quiz

We invite YOU to a fun night of:
**A LITTLE BIT OF THIS,
A LITTLE BIT OF THAT**
TO SUPPORT
BRAIN CANCER RESEARCH AND PATIENT ADVOCACY

When: Sat 13 October 2018
Where: Coorparoo Bowls Club
Time: 6:30pm – 10:30pm


- \$25 per person.
- Inclusive Savoury & Sweet platters per table
- Drinks at club prices
- 8 – 10 per table or just book a seat and we'll find you a team

Every 5 hours someone in Australia is diagnosed with Brain Cancer.
Let's do something to help

Supporting


To Book:
Call Jenny on 0408 188 535
or email jenny.r.loyd@gmail.com


Please join us for the
**4TH ANNUAL
WHITE PEARL BALL**
in aid of brain tumour research
and supporting
The Brain Cancer Group
From Care2Cure
formerly The Sydney Neuro-Oncology Group (SNOG)
Enjoy entertainment by
RAT PACK RELOADED
SATURDAY, 10 NOVEMBER 2018

MARITIME BALLROOM HYATT REGENCY 161 Sussex St overlooking Darling Harbour	7PM \$230 PER TICKET Formal/Black Tie
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TICKETS AND ALL ENQUIRIES:
Suzane 0418 238 723
suzane@wpfundraiser.com.au

Proud partner  Bank of Sydney
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SPREAD THE WORD!

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

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Search 'BTAA' for
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