



**BRAIN TUMOUR**  
ALLIANCE AUSTRALIA Inc.

1800 857 221



**MAY 2023**

BTAA.ORG.AU



# ABTC To Give Better

# Deal For Patients

**INSIDE THIS EDITION**

**LYNETTE WILLIAMS  
HONOURED WITH  
AWARDS AT COGNO**

**DDF - CHANGING  
APPROACH TO  
DIAGNOSIS**

**RCD FOUNDATION'S  
AIM PROJECT**

**GLOBAL SOLO  
CHALLENGE  
FOR BTAA**

**THIS MAGAZINE WAS PRODUCED WITH THE ASSISTANCE OF DONATIONS**



## LETTER FROM THE CHAIR

For many years the mission of Brain Tumour Alliance Australia has been to **Support, Inform, Represent and Connect** brain tumour patients, carers, their families and medical professionals throughout Australia.

**Support** has been provided through our 1800 Helpline service, our support packages for newly diagnosed patients, the support groups we run or link to, and our regular patient forums. Every year hundreds of people are assisted through these programs.

The latest **information** from the brain tumour world is distributed through our biannual magazine, our monthly e-news and Australia's most comprehensive collection of support materials on our website. As well as this, the forums we run or support, bring Australian and international research leaders to speak.

The BTAA has sought to **represent** consumers as representatives on many enquiries and in Federal and State committees and we have tried to work to **connect** the many brain tumour organisations across the country to provide a coordinated and unified voice. This has proven to be a challenge because of the large number and nature of different organisations, until now.

The Australian Brain Tumour Collaborative will bring major brain tumour organisations together in a collaborative group that will be sure to provide better outcomes for all Australians affected by a brain tumour. A full report on the ABTC is in this magazine, but congratulations must go to all who have contributed to this ground breaking advance.

A number of fantastic programs are currently being offered by universities and brain tumour groups across the country. I would like to strongly encourage readers to consider joining into those programs suited to your circumstances. You will not only gain benefits for yourself, but will help others in the program by your participation. The programs that involve university research will also provide benefits to many in the future.

Early in May, the Brain Tumour Group in conjunction with the BTAA, will be holding a patient symposium in Sydney called "What Can Be Done If My Brain Tumour Relapses?" You can attend in person, watch online, or view a recorded version later. Previous forums have been outstanding and highly rated by our members. To register, see more information and the flyer in this magazine.

The BTAA is the national brain tumour support group and is run entirely by volunteers who are either brain tumour patients, family members or carers. Their tireless work, manning the 24/7 Helpline, running support groups, managing our finances, keeping our Facebook and webpages up to date, producing our publications, and sending our information packs, is the core of our work. Because of this we have very low overheads and are able to run almost entirely on donations made by the public.

I would like to thank those who have donated to BTAA this year. Your generous contributions will allow us to continue our work to Support, Inform, Represent and Connect brain tumour patients across Australia.

<b>Daniel Petre</b>	<b>\$1000</b>
<b>Julia Reed</b>	<b>\$200</b>
<b>Michael Love</b>	<b>\$250</b>
<b>Robyn Holt</b>	<b>\$200</b>
<b>Graham O'Kell</b>	<b>\$5000</b>

**Craig Cardinal  
ChairC**



Craig's wife, Berlinda, was diagnosed with high grade brain cancer in October 2015. Craig joined BTAA after years of experiencing and witnessing the struggles of brain tumour survivors, families and carers whilst navigating services and supports in Australia.

Craig spent close to 30 years with defence and served in the Royal Australian Air Force, Royal Australian Navy and as a public servant with the Department of Defence. Craig also served with the Australian Customs and Border Protection Service and has consulted and contracted to industry, state and Commonwealth governments.

Craig is passionate about contributing to the improvement of services and supports for brain tumour sufferers and families.



### Patient Education and Information Forum

#### WHEN

Friday 5th May 2023 - 10.00am to 2.30pm

#### WHERE

Education Centre, North Shore Private Hospital

#### TOPIC

"What can be done if my brain tumour relapses?"

*Detailed program and speakers will be available soon.  
Online streaming option available for interstate attendees.*



Registrations now open on  
[btaaforum2023.eventbrite.com.au](https://btaaforum2023.eventbrite.com.au)

## SAVE THE DATE!



### 15th COGNO Annual Scientific Meeting

COGNO is pleased to announce that planning is underway for our upcoming ASM and associated meetings to be held from Sunday 8th October – Wednesday 11th October in Sydney. To join our mailing list for regular updates, email [ctc.cognoasm@sydney.edu.au](mailto:ctc.cognoasm@sydney.edu.au) with your interest. We look forward to welcoming you in October!

**Sunday 8<sup>th</sup> October – Wednesday 11<sup>th</sup> October 2023  
Sydney, NSW, Australia**

More information  
[www.cogno.org.au](http://www.cogno.org.au)





COVER STORY

# ABTC To Give Better Deal For Patients

## Australian Brain Tumour Collaborative Established

The Australian Brain Tumour Collaborative (ABTC) held its inaugural steering committee meeting on 9 December 2022. The Collaborative aims to develop and convey a united national voice that provides consolidated and evidence based advocacy to governments, stakeholders and the Australian brain cancer patient, family and carer community. This advocacy seeks to clearly define key issues and national responses that achieve better support and outcomes for individuals, carers and families impacted by brain tumour in Australia. In particular, responses and actions to minimise the significant challenges the disease and treatments present to consumers from date of diagnosis and through the survivorship journey.

The Collaborative's objectives are as follows:

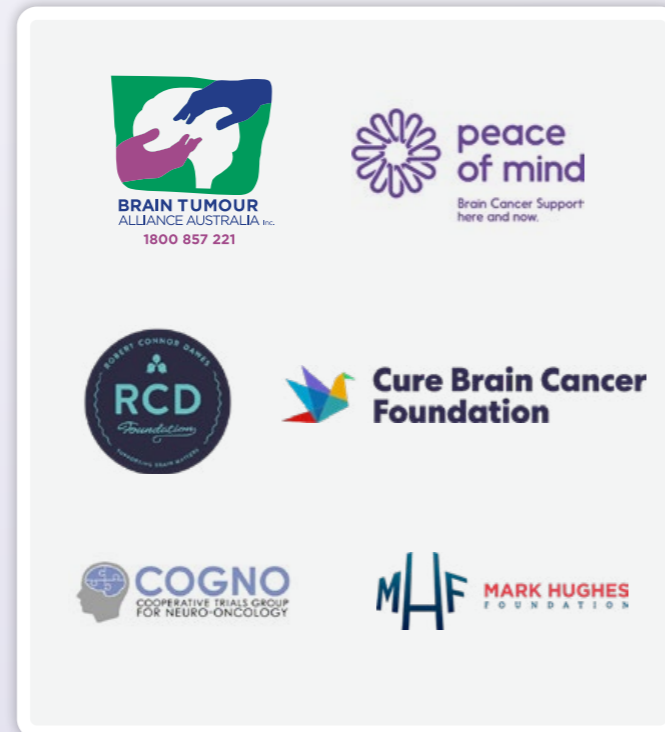
- Identify and promote understanding of key gaps in services and support for people impacted by brain tumour.
- Promote integration, partnerships and information sharing within the national brain tumour sector that better supports people impacted by brain tumour.
- Promote patient-centred solutions to challenges associated with the survivorship journey for people living with brain tumour, drawing on evidence based research and lived experience.
- Individually and collectively advocate for better access to service coordination and ongoing supports for people with brain tumour and for the continuing research and clinical trials to inform prevention, treatment and care.

The committee selected Mr Craig Cardinal from the Brain Tumour Alliance Australia (BTAA) to be the inaugural chair of the ABTC steering committee.



On the front cover Canberra Support Group members: Craig Fitzgerald, Peter Wynn, Pat Wynn, Vicki Dabro, Cheryle Henry, Matthew Henry, Grace Henry

There are currently seven foundation member organisations of the Collaborative. These members include organisations with focus on patient support and survivorship, best practice clinical care and research interests and are as follows:



The Collaborative's steering committee has endorsed a governance framework and commenced development of an initial road map identifying opportunities and priorities for patients and consumers for the next 12 months.

The Collaborative will be writing to government and other key stakeholders to communicate its establishment and to identify early opportunities to improve outcomes for people impacted by brain tumour.

Importantly, the ABTC recognises and supports the individual objectives and achievements of all Australian brain tumour support providers and stakeholders. The ABTC seeks to enhance current critical initiatives – such as, the Australian Brain Cancer Mission – through recognising and supporting these various initiatives.

## Vale: Harry Parsons



Harry died peacefully just after midnight on 5 March, aged 37 years, with loved ones all around. He had battled a brain tumour for a number of years, and readers will remember he contributed to these magazines on a number of occasions, sharing his world and his philosophy as a young person struggling with a brain cancer.

It was time; he was ragged with exhaustion and ragged with the impact and endurance of a recent clinical trial. Harry tried many different treatments, and in the end Lomustine and Avastin, but in all these 8 years he never complained - grumbled yes, but never complained or pitied his lot.

Harry was a high achiever; star sportsman, entrepreneur, traveller, adventurer, ladies' man and lots besides. He loved giving gifts and he had a compulsion for online shopping. He was a family man and he was massively loved and will be greatly missed.

Harry's mother, Alice, has been a long time active member of the BTAA committee and was a coordinator of the BTAA Sydney Support Group at the Lifehouse Centre. Harry will be greatly missed by his family and friends, and the BTAA would like to send their sincere condolences to the family.

SAVE THE DATE

## The Future of Brain Cancer Care: Supporting People Better

The BRAINS Program is proudly hosting a virtual early and mid-career researcher (EMCR) showcase.

This showcase brings together EMCRs from many research programs across Australia who will share their research on ways to better support people diagnosed with brain cancer, their caregivers, and the health professionals who work with them.

This event is open to anyone interested in attending including researchers, clinicians, people with brain tumour, and caregivers.

WHEN

WEDNESDAY  
14TH JUNE 2023  
12.00PM – 1.30PM AEST

COST

FREE

WHERE

ONLINE EVENT

### HOW TO REGISTER



SCAN QR CODE OR VISIT

<https://www.eventbrite.com.au/e/the-future-of-brain-cancer-care-supporting-people-better-tickets-590611955257>





## Daniela Dwyer Foundation Works to Change the Approach to Brain Tumour Diagnosis

The Daniela Dwyer Foundation is a registered charity aimed at changing the approach to diagnosing and treating cancer patients. The Foundation is supported by the QIMR Berghofer Medical Research Institute, where Daniela's blood samples provided invaluable information for Professor Sudha Rao's ground-breaking liquid biopsy testing regime.

Daniela, affectionately known as Dee, was diagnosed with aggressive brain cancer at the young age of 33, despite leading a healthy and fit lifestyle. She participated in half-marathons, triathlons, and fundraising bike rides, and enjoyed going to the gym and Perth's beautiful beaches with her beloved Rhodesian Ridgeback, Louie. She had suffered migraines since her teenage years, but in the months leading up to her diagnosis, Dee felt unusually tired and her migraines became more frequent. Unaware that her headaches were a sign of anything more sinister, Dee continued to stay active. However, while out walking with friends, she noticed her right foot catching on the footpath, which was the beginning of her journey through surgery, chemotherapy, and radiation.

Dee's treatment journey led her partner and family to establish the Daniela Dwyer Foundation, which aims to fund projects to improve outcomes for brain cancer patients. During Dee's treatment, the Foundation had the privilege of working with Professor Rao and her research team. Professor Rao's liquid biopsy testing

can predict the characteristics of a patient's circulating tumour cells and how responsive they may be to therapeutics. This testing can inform oncologists immediately if a patient is responding to chemotherapy treatment, enabling them to adjust or change the treatment to maximize the effect on the circulating cancer cells. This means that patients' lives could be positively extended. Using Dee's blood samples, Professor Rao was able to show that a new drug Dee was being treated with had promising effects. Sadly, it was too late to make a difference for Dee, but her contribution to the research has the potential to help future patients.

Dee's story highlights the importance of early diagnosis and appropriate treatment in the outcome of patients with brain cancer. Brain cancer treatment has not changed significantly in over thirty years, and it continues to be one of the deadliest forms of cancer, particularly among people under the age of 40. This underscores the urgent need for innovative approaches to diagnosis and treatment.



Fortunately, the Daniela Dwyer Foundation is working to change the approach to diagnosis by offering an alternative to current treatment options so that early intervention and liquid biopsy testing become routine for those beginning their brain cancer journey. The Foundation is striving to fund projects that will improve outcomes for patients in the future, starting with supporting Professor Rao's liquid biopsy test. If every oncologist requests the blood test, the Foundation will have achieved a remarkable milestone of change in the future treatment of brain cancer. The ultimate goal would be that this blood test would be something every GP could request, as a routine check for cancer cells, even before a diagnosis of cancer.

Dee's partner and family are comforted and proud that Dee has contributed to Professor Rao's valuable research. Dee would have wanted to do everything possible to make a difference, to "change the changeables." We truly believe that she has paved the way for remarkable and tangible changes in the way brain cancer is treated.

Dee's legacy lives on through the Daniela Dwyer Foundation, and her story serves as a reminder of the urgent need for improved brain cancer treatment. By supporting the Foundation's work, individuals and organizations can help make a difference in the lives of brain cancer patients and their families. All donations are tax-deductible, and every contribution helps bring us closer to a future where brain cancer is no longer a devastating diagnosis.

To learn more about Dee's story, Professor Rao's research, and the work of the Foundation, visit [www.danieladwyerfoundation.org.au](http://www.danieladwyerfoundation.org.au) or scan the QR code below.



### Peace of Mind Foundation Big Day Outs!

Hosting events all across the country in 2023/24



Check our online event page for more details...



[www.peaceofmindfoundation.org.au](http://www.peaceofmindfoundation.org.au)  
[info@peaceofmindfoundation.org.au](mailto:info@peaceofmindfoundation.org.au)

- @peaceofmindfoundation
- @peaceofmindfoundationaustralia
- Peace of Mind Foundation Australia



# Lynette's life honoured with awards at COGNO

Billy Williams

Two awards focused on supportive care for brain tumour patients and carers were presented at the recent conference of the Cooperative Trials Group for Neuro-oncology (COGNO) held in Brisbane. The awards honour the life of Lynette Williams who bravely fought a glioblastoma multiforme (GBM) before succumbing to the disease in 2017. The Award is a result of a partnership between the Ghana-Australia Association and the BTAA to hold a fundraising event in Canberra. Subsequently, BTAA and COGNO agreed to establish the BTAA Lynette Williams Award with an annual competition for the best poster presentation for supportive care.

The winners of the award for 2022 were:

### First prize

'Developing a stepped care model for assessing unmet needs in people diagnosed with high grade gliomas; defining criteria for stepped care intervention'. A/Professor Joanne Shaw, University of Sydney and Curtin University, Perth

### Second Prize

Efficacy and toxicity profiles of linear accelerator-based hypofractionated stereotactic radiosurgery in the management of intact brain metastases; Dr Quichen Zhang, Department of Radiation Oncology, Peter MacCallum Cancer Centre, Melbourne and University of Melbourne.

Entries for the best poster presentation for supportive care will be due soon for COGNO 2023

Lynette's husband, Billy, is a BTAA committee member and coordinator of the 1800 Helpline service. 'While the terrible loss of Lynette has left a lasting shadow over the lives of my family, the support provided through BTAA and the establishment of an award in Lynette's name, provides a positive and lasting legacy, encouraging efforts for better supportive care services for those on this journey', Billy said.



Lynette and Billy in happier times looking forward to retirement.

**Background**  
People with brain cancer may experience a range of symptoms and needs. These may be physical, behavioural, cognitive, or psychological. These symptoms and needs arise due to changes in the brain structure and function and side effects of treatment. The severity of symptoms and the level of need varies across individuals and the disease trajectory, influencing the support required.

**Method**  
We adapted published criteria by Boyes et al. (2015)<sup>1</sup> for defining level of unmet need using the SCNS-ST34 (brief version of the SCNS-ST34). We modified their criteria from 3 levels to 4 levels:

Level of need	Definition
No need	Selected 'no' need for help for all items
Low need	Selected 'low' level need for help for at least one item but did not select 'moderate' or 'high' level need for any item
Moderate/high need	Selected 'moderate' or 'high' level need for help for at least one item
Low or Moderate need	Selected 'low' or 'moderate' need for help for at least one item but did not select 'high' need for any item
High need	Selected 'high' level need for help for at least one item

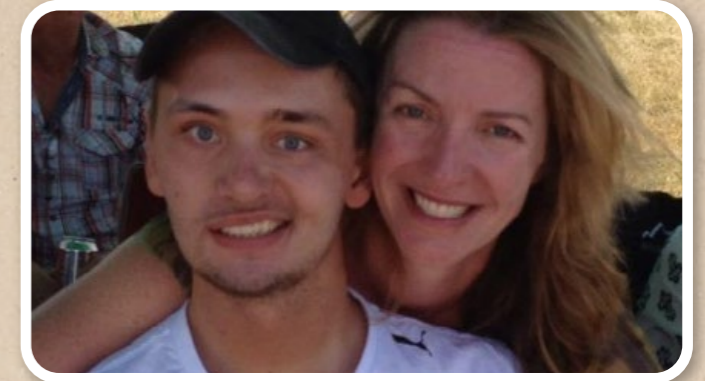
**Results**  
Of the 116 participants, 13% (n=15) were classified as Step 1, 23% (n=27) Step 2, 24% (n=28) Step 3, and 40% (n=46) Step 4.

	Step 1 No need	Step 2 Low need	Step 3 Low or moderate need	Step 4 High need
<b>OVERALL</b>	15 (13%)	27 (23%)	28 (24%)	46 (40%)
Psychological	53 (46%)	23 (20%)	24 (21%)	16 (14%)
Health system and information	62 (53%)	19 (16%)	11 (10%)	24 (21%)
Physical and daily living	33 (28%)	34 (29%)	30 (26%)	19 (16%)
Patient care and support	86 (74%)	17 (15%)	9 (8%)	4 (3%)
Sexuality	84 (72%)	13 (11%)	11 (10%)	7 (6%)

**Contact**  
Dr Mona Farris  
mona.farris@sydney.edu.au  
@MonaFarris23

First prize winning entry  
'Developing a stepped care model for assessing unmet needs in people diagnosed with high grade gliomas'

# A New Approved Molecular Diagnostic Test Changing the Odds For Kids With Brain Cancer in Australia



Connor and Liz Dawes

One of Connor's wishes was that no other young adult or child would have to go through what he experienced. Sadly, Connor lost his battle with brain cancer (ependymoma) at the age of 18 years. Inspired by her son, Liz Dawes begun the Robert Connor Dawes Foundation in his memory with a firm commitment to change the odds for kids with brain cancer. In addition to a unique home based music therapy program for support, the majority of funding goes towards research into paediatric brain cancer. Liz and the Foundation have worked tirelessly to fulfil Connor's wish. On the 10th anniversary we are proud to announce that we really have with the help of cofunders started to move the dial for kids with brain cancer with a certified diagnostic test that is now available in the clinic for all Australian and New Zealand children with brain cancer. Importantly, it can change the diagnosis and treatment plan in up to 20% of cases.

It all started with Liz Dawes, the Foundation CEO, chatting with a leading expert in the field, Dr Amar Gajjar from St Jude's Children's Hospital in the United States, at the MCG whilst on a visit to Australia to explore research collaborations. Dr Gajjar strongly believed to make any impact, investing in research to assess a tumour molecular test for its diagnostic value would be worthwhile. Further conversations with Professors Jordan Hansford and Nick Gottardo and other colleagues, agreed this was an important piece of research to support. Moreover, it was one of the tests being performed as part of the Zero Childhood Cancer Program.

From there, the concept grew into AIM BRAIN Project. Liz actively sort additional funding and successfully secured it from Cancer Australia and Carries Beansies 4 Brain Cancer. The project was a clinical trial administered through the Australian and New Zealand Haematology and Oncology Group (ANZCHOG). It was conducted across Australia and New Zealand to use this molecular testing on tissue from kids brain tumours. The test essentially examines the molecular signature which correlates with features on the tumour DNA in particular places. It is known as DNA methylation profiling.

In conjunction with histological methods and other genetic information, it is able to distinguish between different tumour types, allowing for more accurate diagnosis and tailored treatment plans. The project started in 2017 and the trial only closed this year. Results were analysed in Australia and sent for verification to the German Cancer Research Centre (DKFZ) where Professor Stefan Pfister was undertaking the same study on a larger scale called MNP2.0. Results showed 99% concordance across the two groups validating it as a diagnostic test.

The sector was extremely encouraged by these results and the RCD Foundation together with WEHI, funded the translation of this research into the clinic. This is no mean feat, as it requires all the technical knowledge and expertise to be transferred as well as the equipment and new laboratory to meet required standards, in order for the test to be accredited by the regulatory body called NATA. Recently, this accreditation process for the test performed at the Victorian Clinical Genetics Services (VCGS) at the Royal Children's Hospital in Melbourne was achieved. The last piece of the puzzle which our Foundation is now exploring, is the appropriate pathways to apply to government to try and get some of the test costs subsidised.

This work is a rare example of "true" translation from the research sector to the clinic where it have an significant impact for children with brain cancer. We are proud to say that this now places Australia alongside the United States, Canada and United Kingdom as one of the few countries world-wide to offer clinically validated methylation profiling for brain tumours.

We will never stop trying to make Connor proud and help other kids with brain cancer. If you wish to join the fight and make a big impact please contact Liz Dawes on [liz@rcdfoundation.org](mailto:liz@rcdfoundation.org).







# Brain Tumour Alliance Australia Committee 2023

The BTAA Committee is elected at the Annual General Meeting of members each November. All committee members are volunteers and either brain tumour patients, carers or family members.



**Craig Cardinal**  
CHAIR

Craig's wife, Berlinda, was diagnosed with high grade brain cancer in October 2015. Craig joined BTAA after years of experiencing and witnessing the struggles of brain tumours survivors, families and carers whilst navigating services and supports in Australia.

Craig spent close to 30 years with defence and served in the Royal Australian Air Force, Royal Australian Navy and as a public servant with the Department of Defence. Craig also served with the Australian Customs and Border Protection Service and has consulted and contracted to industry, state and commonwealth governments.

Craig is passionate about contributing to the improvement of services and supports for brain tumour sufferers and families.



**Catherine Hindson**  
VICE-CHAIR AND HELPLINE

Catherine joined BTAA after her daughter Renee was diagnosed with an anaplastic astrocytoma in 2010. Since then Catherine has held many roles, serving as Treasurer and Vice-Chairperson before being elected Chairperson in 2016, and then Vice-Chair in 2022. Catherine's passion is to make sure every person diagnosed with a brain tumour is able to access information and support.

She holds a Bachelor of Nursing (post registration) from Deakin University and has enjoyed a 42 year career as a Registered Nurse working in operating theatres around Australia. The last 18 years of her career were spent in operating theatre management, ultimately managing 120 staff across a 10 theatre, multi-campus hospital group.

Catherine took early retirement in 2006 to become a full time carer to her late husband Bill, who passed away with multiple myeloma in 2017. She lives in Canberra where her two daughters, and her three grandchildren are nearby. Renee is now 45 and still doing well.



**Pat Wynn**  
TREASURER

Pat's husband Pete has had three craniotomies, the first in 1988, the second in 2004 and the most recent in 2015. He has had a low grade Oligodendroglioma, ranging from Grade 2 (the most recent) to Grade 3-4 for the previous two.

Pat had never previously sought support until after the 2015 recurrence, when the effects of anti-seizure medication and 3 tumours started to have a more significant impact on their lives. Being able to connect with people going through similar situations has been beneficial in helping them deal with their 'new normal' life.



**Diane Dunn**  
SECRETARY

In November 2016 I received a diagnosis of Grade 2 oligodendroglioma in my right parietal lobe and was advised it was inoperable. In common with most brain tumour patients, I was completely blindsided by this unexpected diagnosis. Prior to this, I was a very fit 54-year-old - vegetarian since 18, a non-smoker, and a non-drinker.

As a result of my diagnosis, I lost my small business - I was the sole owner/operator of a boutique bakery and, as is often the case for self-employed people like myself, I didn't have leave entitlements to fall back on.

I have a wonderfully supportive husband Philip, and three adult children. I am still an avid baker and live on a blissful bushland property in the foothills of the Brisbane Ranges in Victoria with two adored dogs.

I look forward to being able to contribute to the work of BTAA, as I have a burning desire to bring awareness of brain cancer to the forefront of cancer discussion in this country.



**Philip Steel**  
EDITOR

Philip was diagnosed with a Right Parietal Meningioma in 2011 and had a successful craniotomy shortly thereafter. Following a few months rest and recuperation Philip was able to return to his work as a high school principal, despite some adverse effects from the tumour and surgery.

Philip joined the Canberra Support Group in 2011 and has been a regular participant ever since. Now retired, Philip has been a Committee Member, assistant secretary and Vice-Chair of the BTAA and currently manages the "Inform" area of the organisation, which produces newsletters, magazines and organises publications for the patient information pack.



**Pam Hubner**  
COMMITTEE MEMBER

Pam's daughter was diagnosed with a brain tumour in 2011, 2 months before her 37th birthday.

She found the challenges of helping to support an adult child rather daunting and attended a Cancer Council forum in Brisbane.

There was some information there about BTAA, a national body to help Brain Tumour patients and their carers. Always wanting more information, to be able to help her daughter navigate this journey, Pam found that by joining as a member, it gave her access to much more information and resources to achieve this goal.

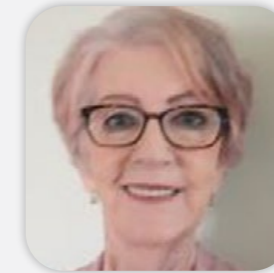
After being told her daughter's tumour was inoperable, it was through the information received from BTAA that Pam learnt the importance of asking questions and the seeking of a second opinion. It is now with deep sadness, that at the age of 44 after an almost 8-year journey, Angie passed away on the 27th October 2018 leaving behind a husband and three young children.

Pam lives in Queensland and continues, when she can, to assist BTAA with their endeavours for ongoing support for Brain Tumour/Cancer patients and their families



**Billy Williams**  
COMMITTEE MEMBER AND HELPLINE COORDINATOR

Billy's wife Lynette passed away from a glioblastoma multiforme in 2017. It was the realisation of the impact the disease had on his family over a two year period that has led him to serve on the BTAA's committee. He has received strong support through the monthly meetings held in Canberra. He has three adult children and two grandchildren. Billy is a retired diplomat who served overseas in Africa and South East Asia.



**Di Pooley**  
COMMITTEE MEMBER AND MENINGIOMA FACEBOOK GROUP COORDINATOR

Pam entered the Brain tumour world 34 years ago, losing a young, very close loved one to this insidious disease. Then in 2015, I became unwell and was eventually diagnosed with a large 8cm meningioma on my brain, which was successfully removed 24 hours after it was first identified. Tragically, my older sister was admitted to the same hospital, 2 days after my surgery, and was diagnosed with multiple metastatic brain tumours. She has since passed away.

I am retired with a background in health care and planning, ranging from aged care nursing to residential lifestyle development, and dementia management, training and education. I manage the online Australian Meningioma Support Group which has 412 members and is growing daily.

I became involved with BTAA some time ago and am part of the Sydney Peer-to-Peer Support Group Leadership Team. This group is very welcoming, proactive, informative and for me, it is a place to provide a voice for the many primary benign brain tumour survivors.



**Peter Ramstadius**  
WEBSITE COORDINATOR AND HELPLINE

Peter is a semi-retired civil engineer from Coffs Harbour. He has enjoyed a varied career specialising in construction project management for both government and the private sector, but more recently in a self-employed role working in the mining industry. Peter became involved in the brain tumour community when his wife, Jenelle developed a GBM and passed away in 2017 after a 20-month battle. Jenelle had had an unrelated meningioma removed a few years earlier.

Peter has four adult children and is keen to utilise the knowledge gained through his wife's journey to assist others.



**Bernadette Power**  
COMMITTEE MEMBER



**Kate Brown**  
COMMITTEE MEMBER



# Global Solo Challenge for BTAA

**Intrepid sailor and BTAA supporter, Kevin Le Poidevin, will soon be heading to Spain to finalise preparations for the Global Solo Challenge sailing event on his yacht Roaring Forty. The Global Solo Challenge is a single-handed, without assistance, around the world, sailing event, with a unique format.**



Kevin Le Poidevin

It will depart from A Coruña, Spain in August 2023. The event is for sailors on a wide range of boats seeking the challenge of a competitive solo circumnavigation under the umbrella of an affordable, well organised and controlled event that puts the safety of participants first. The format is unlike any other round the world event and will make it fair and exciting for the Skippers as well as easy and engaging for the public and sponsors to follow:

Boats will be grouped by performance characteristics and set off in successive departures over 3 months. Once at sea, there are no classes. All boats will be sailing the same event. The faster boats will have to try to catch up with the slower boats, the pursuit factor creating competitive interest aboard and a fascinating event for the public and sponsors. The first boat to cross the finish line wins. The performance differential between the boats is taken into account in staggering the departures, eliminating the need to calculate corrected times.

Kevin, age 61, lives in Port Stephens, and has competed in many ocean classics, including the 2012 Rolex Sydney Hobart Yacht Race, raising funds for the BTAA and the Soldier On group in his yacht Rogue Wave. Kevin was a great supporter of Nathan Draper, a popular Canberra Support Group member, and regular contributor to the BTAA magazine, who sadly passed away this month after a long battle with brain cancer.



Kevin writes,

*"Sadly, my wife Narrelle and I attended Nathan 'Bullet' Draper's funeral at the RMC Chapel last week. Great tribute to a wonderful bloke and loving family man. Christine has been amazing and a rock for Will and Zac.*

*Always a memorable moment when a military mate passes and the last post and rifle volley are played out. Every time I hear the last post, it's my mates that are automatically front and centre in my thoughts.*

*It was very fitting that the Air Force named a Conference Room in Nathan's honour.*

*A few weeks prior to his passing, I drove down to Canberra to visit when Christine said his condition was rapidly declining. Had a wonderful couple of days visiting Bullet, Christine and the boys and devoted sister Caroline. Bullet was upbeat and pragmatic as usual even though he knew the end was near. That engineering brain of his was still eager for more knowledge about my Global Solo Challenge (GSC) campaign. So grateful we had that opportunity to spend time together.*

*My GSC campaign is still on track and the BTAA logo is proudly displayed on my GSC Entry profile page and it links directly to the BTAA fundraising page. I sincerely hope it helps raise awareness and funding for BTAA."*

**When asked what his biggest challenge in the race would be:**

*"Upon reflection, the biggest challenge has been not having Roaring Forty in Australia 24/7 for me to progress jobs without handing over budget funding to a contractor. This situation is a major cost driver. However, given the logistics, weather, wear and tear and other risks involved, if I had to sail Roaring Forty to the start line in Spain from Australia, I think the loss balances out the risk, since Roaring Forty now sits in A Coruna awaiting my return."*

**Do you intend to link this personal challenge with a social message?**

*"Yes, definitely. Through my [Aviator Ocean Racing](#) campaign, collectively we will support two wonderful charity organisations; [Brain Tumour Alliance Australia \(BTAA\)](#) and [Soldier On](#).*

## Nathan "Bullet" Draper

22 March 1970 - 13 February 2023

### Brain Tumour Alliance Australia

BTAA supports brain cancer patients just like our young mate Bullet who documented his 'warts-n-all' brain cancer journey in his blog, [The Tumour Trip](#). Sadly, Nathan lost his battle with brain cancer and passed away in Feb 22. I encourage you to pause your hectic life for a moment, and step into Bullets world. RIP buddy.

The wonderful folk associated with BTAA all have a story that connects them in some way to brain cancer; either as a patient, caregiver, family member or friend. Now they freely volunteer their time to BTAA so they can help provide support to not just the patients, but their families and caregivers.

BTAA do not receive government funding, and rely on the generosity of our community for support so they may continue their great work supporting the families and patients diagnosed with brain cancer.

Please consider digging deep and donating to BTAA; but just as importantly, we need you to carry the message to raise community awareness of the support available through BTAA to help take some pressure off those impacted by brain cancer.

### Soldier On

Established in 2012 with a mission to focus support on post 1990 military veterans, Soldier On aims to help enable veterans and their families to thrive by providing a connected and holistic model of support in their transition journey.

Soldier On offers a full range of support services across health and wellbeing and social participation, including psychological support for better mental health, education and employment, as well as facilitation of social connections through sports and community networks, and advice on staying fit and healthy.

Please give what you can to support [Brain Tumour Alliance Australia \(BTAA\)](#) and [Soldier On](#).

If you are super keen to help this old fella out in return for global brand exposure, then drop me a line and we can discuss sponsorship opportunities. Link to my personal [Roaring Forty Crowdfunding Appeal](#)."

Read more: [www.globalsolochallenge.com](http://www.globalsolochallenge.com)





SAVE THE DATE

## Mark Hughes Foundation Brain Cancer Forum

The annual Mark Hughes Foundation Brain Cancer Forum is on again this year for those in the Hunter and the north of NSW. Each year there is a great program of expert speakers and a chance to meet others sharing your experiences. This day is always highly rated by attendees and is well attended by patients, carers and family members.

Follow the links on the [Mark Hughes Foundation website](https://www.markhughesfoundation.com.au) for more information coming out soon.



WHEN

FRIDAY MAY 26TH  
2013, 10.00 AM

WHERE

SOUTHS LEAGUES CLUB  
46 LLEWELLYN STREET  
MEREWETHER NSW 2291

## Mark Hughes Foundation Beanies

It's almost that time of year! The 2023 Mark Hughes Foundation Beanies are coming...

We are celebrating our 2023 Beanie campaign for the whole month of June!

Register now to host a Beanie Day at your sporting club, school or workplace here - <https://beanie.markhughesfoundation.com.au/how-can-i-help/host-a-beanie-day/>

We are excited to announce that the NRL Beanie for Brain Cancer Round will be June 29 - July 2.

All money raised during the Beanie for Brain Cancer Round goes directly to brain cancer research.

Be prepared and get your new 2023 beanie June 1 from participating Lowes & IGA stores or you can purchase at any game during Round 18 (excluding NZ).



**MARK HUGHES FOUNDATION beanie FOR BRAIN CANCER**

### HOST A BEANIE DAY

IT'S AS EASY AS 1, 2, 3!

- 1. PICK A DATE**  
Pick a date during Beanie Month (June) to host your beanie day. Or, you can choose anytime that suits you and your guests.
- 2. REGISTER YOUR BEANIE DAY**  
Register your Beanie Day Online so we can stay in touch and help you make the most of your efforts.  
[beanie.markhughesfoundation.com.au/how-can-i-help/host-a-beanie-day/register-your-fundraiser/](https://beanie.markhughesfoundation.com.au/how-can-i-help/host-a-beanie-day/register-your-fundraiser/)
- 3. Plan to Have Fun**  
Be creative, and use your imagination your Beanie Day Fundraising ideas are Limitless. Check out the handy Beanie Day Check List and some helpful Fundraising Tips to get the ball rolling.

## GREY MAY BRAIN TUMOUR RESEARCH UPDATE

### Grey May Brain Tumour Research Update - Lab Tour & Lunch



Raising Awareness for Brain Tumour Research in South Australia

Saturday 13 May 2023 10.00AM  
FREE ENTRY

University of South Australia  
Centre for Biology  
Bradley Building,  
North Terrace Adelaide SA 5000

#### EVENT INFORMATION

[www.nrf.com.au/events/go-grey-in-may](http://www.nrf.com.au/events/go-grey-in-may)

#### HOW TO REGISTER

<https://drct-nrf.prod.supporterhub.net/events/grey-may-research-update>



## Sapphire Coast Turf Club Supports BTAA

At a recent race meet, the Sapphire Coast Turf Club sponsored the BTAA in one of its races. The club is based at Bega on the NSW South Coast and community members were aware of the work of the BTAA after some brain tumour cases in the region.

It is important to ensure that patients diagnosed with a brain tumour in regional areas, and away from major hospitals and nurse care coordinators, know of the support that can be provided by the BTAA through their support line and information packs. Community events like this are a great opportunity to publicise our work.

BTAA Committee member, Bernadette Power, (shown right), attended and presented the winning trophy. The BTAA has been invited to be involved in coming race days as well.







**NEED SUPPORT NOW?**

**PHONE 1800 857 221**



To talk with experienced caregivers, call BTAA on the Support number: **1800 857 221**, and see the support groups available in your local area at [www.btaa.org.au](http://www.btaa.org.au) – look for support organisations.

Cancer Connect telephone (**13 11 20**)

Brain Tumour Patients Telephone Support Group  
Support Line **1300 755 632**  
Monday - Friday 9am - 5pm  
or email [tsg@nswcc.org.au](mailto:tsg@nswcc.org.au)

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

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

## SPREAD THE WORD!

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

**1800 857 221**

**[www.btaa.org.au](http://www.btaa.org.au)**



*Brain Tumour Alliance Australia*



*@BrainTumourAA*



*Search 'BTAA' on YouTube*



**BRAIN TUMOUR**  
ALLIANCE AUSTRALIA Inc.

**1800 857 221**

Editor **Philip Steel**

Designed by **Jon Shirley**

Printed by **Mavericks Printers**

Authorised by  
**Craig Cardinal**, Chair,  
PO Box 717, Mawson, ACT 2607

Disclaimer: The material provided in this Newsletter and on our website is general in nature. It is made available on the understanding that BTAA is not engaged in rendering professional or medical advice. Before relying on the material users should carefully evaluate its currency, completeness and relevance for their purposes, and should always obtain appropriate medical advice relevant to their particular circumstances.