INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK EDITION

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.
1800 857 221

OCT 2021
BTAA.ORG.AU

Racing for BTAA

INSIDE THIS EDITION

- ANKIT WALKS FOR HIS BROTHER
- FIONA CAN GUIDE ON NDIS ISSUES
- HEAD TO THE HILL
- ENGAGE TO SUPPORT CHILDHOOD BRAIN TUMOUR SURVIVORS

THIS MAGAZINE WAS PRODUCED WITH THE ASSISTANCE OF DONATIONS

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NEED SUPPORT NOW?

PHONE 1800 857 221

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

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** – 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

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

Email btaa@shout.org.au

COGNO
COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

BRAIN TUMOUR
ALLIANCE AUSTRALIA Inc.

UPCOMING EVENT

The COGNO Patient Education and Information Forum

WHEN SUNDAY 24/10/2021 10:30 AM

WHERE Online

EVENT DETAILS

All brain tumour patients, carers and their families are invited to participate in our online forum. Hear about the latest research and treatments from leading International and Australian experts. Interact with other members of Australia's brain tumour community.

Join us for our Online Event to take place as part of COGNO Annual Scientific Meeting 2021. All welcome.

REGISTER NOW!

www.btaa.com.au

EVENT BRITE BOOKING

SCAN HERE

TAP HERE

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care2cure
THE BRAIN CANCER GROUP

LETTER FROM THE CHAIR

Greetings from Lockdown in Canberra. Unfortunately, Covid Issues still prevail.

In May we were very fortunate in being able to co-host the **Patient Education & Support Forum** with **The NSW Neuro-Oncology Group**. The Sydney forum was well attended and we followed all COVID safety precautions, questions were written, no sharing of microphones etc. The forum has now been held every year since 2004. This year the speakers were: Doctor's Jonathon Parkinson, Michael Back, Hao-Wen Sim, Liz Hovey, Ben Kong, and Andrew Cole with Nurse Practitioner Marina Kastelan and Sally Carvin from the Cancer Council.

The video of the day is available on our website: https://www.youtube.com/watch?v=8N89TAGA1Yk

Covid struck again! We were planning the first **Meningioma Educational Forum** with **The Brain Cancer Group Care2Cure** in July. We were forced to change our plans to a virtual event to which 106 people registered. The online forum was an outstanding success and we hope to repeat this again in our October COGNO Patient Forum. (See more information on this in a separate article in this magazine)

There is a story/article on the forum in the magazine and a video of the forum is also available on our website http://www.youtube.com/watch?v=BDu8v36dB1w

The Brain Cancer Group Care2Cure will be holding additional educational sessions next year.

Last year, Annual Scientific Meeting for **Cooperative Trials group for Neuro-Oncology (COGNO)**, was cancelled because of COVID. This year it will be Virtual from Sunday 24th to Tuesday 26th October 2021.On the Sunday there will be a virtual **Patient education & Support Forum**. To register go to https://btaaforum.eventbrite.com.au.

Additional information on topics and speakers will be forwarded to our subscribers when confirmed.

I would like to extend a big thank you to this year's committee for their dedication and commitment to BTAA. Even while COVID lockdowns have been in place and all BTAA Committee meetings have been run via Zoom, our committee members have been working hard to represent, support, inform and connect with all of those in Australia's brain tumour community. The Head to the Hill initiative led by Diane Dunne and Catherine Baldwin to raise awareness and foster political support for brain tumour patients, carers and their families in the Federal Parliament, unfortunately has now been postponed due to the lockdown. The National Collaborative for Brain Tumour Survivorship is still being actively pursued by Craig Cardinal and during the course of the year we have seen some great initiatives in this space. Amanda Griffin and Bell Ross has worked to improve our social media presence which now has up to the minute information and news. Di Pooley's Australian Meningioma Support Facebook page is providing great support for all Meningioma patients across the country. The telephone support team of Billy Williams, and Janet Micallef work tirelessly to answer all of the calls on our support line (1800 857 221). Behind the scenes, Peter Ramstadius, Pat Wynn and Philip Steel work to make sure the Website is operating, the accounts are done and our E-news and magazine are published. As always, founding members Susan Pitt and Denis Strangman, provide sage advice on the effective operation of BTAA.

Our organisation is run exclusively by volunteers. By the time you read this magazine, our AGM will have taken place and our committee will be elected. All members have been advised by email of the AGM and related information.

We can always do with more volunteers in each state, to help us in spreading the word of the support available through BTAA. If you are interested in being involved, I would love to hear from you chair@btaa.org.au.

I wish everyone, patients, carers, families, doctors, nurses, health care workers, brain tumour researchers, and brain tumour support groups, a happy and healthy rest of 2021 and that 2022 is free of lockdowns, all borders are open and we can enjoy the company of friends and loved ones.

Catherine Hindson
Chair

The BTAA would like to thank all of those who have given generously to support the work of the BTAA. These include:

Donations from the funeral of Evangelist Tselonis

General donations from ; David Robinson, Caroline Saint, Sharon Moloney, Peter Rich, Susan Pitt, Claire Shoebridge, Kylie Moore, Susan Murrant, Lisa Giesemann, the Hindson's, and Michael Scott from the Nicola Scott Education Grant.

Alice Parsons who ran a successful dinner in the Hunter Valley.

Special thanks to the anonymous donors who have supported us with substantial funds through PayPal.

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

Energy

Harry Parsons

Anyone who has had a cancer journey will tell you how tiring it is. But you bounce back right? After all the treatments have run their course and worn off? Surely! No. At least not for me. And I know I'm not alone in the complete burnt-out, flat-as-a-pancake, don't-want-to-do -a-single thing exhaustion caused by having (and beating) the big C.

So, what can you do? For a long while after finishing my chemo and radio therapies and being regularly sick in the mornings, I thought one day I was just going to wake up clear-headed, alert and ready to take on the day. My doctors said it should just be a matter of time, so I waited and waited, and then I waited some more until I decided that if I wanted to live this life I had been given a second chance at, actually live it – not just meander through it, then I needed to somehow get my energy back. "So, what do you recommend I do, Doc?" I asked them all. All I kept hearing was exercise, exercise, exercise.You're kidding, right?

The longest I spend on my feet every day is ten minutes in the shower, and doing just about anything saps my energy too quickly to fight it; and you want me, in this exhausted state, to strain myself physically, to SPEND what little energy I have, in order to gain some? Come on. I should add at this point that I was also a victim of a stroke following my first surgery in 2015 which took a toll on me physically, and on top of rendering half (left) of my body practically useless, I was idle for so long that my fitness deteriorated very quickly and I packed on weight like it was my job. The concept of exercise, or any physical activity was tiring to even think about.

I remember when I was younger learning that cancer sufferers were always tired. My plucky and energetic former self thought "How can they possibly be so tired?" Oh! how those tables do turn. Turns out these good medical professionals do indeed know what they are talking about. It took some time but I eventually went to a gym and met with a trainer, who, would you believe, had also suffered a life-altering blow to his health – his in the form of being hit by a speeding truck on the side of an American interstate. Not cancer, but equally traumatic.

Mark had been a professional sportsman, in incredible shape and he was scraped off the highway, implanted with metal all over and didn't look remotely like a man of 60 by the time I met him. A real-life wolverine who understood my plight. He trained me for a couple months out of his little fitness studio and taught me how working out was as much a mental game as a physical one, as well as a few new tricks in the gym. We started slowly but eventually I started loving the exercise – blood flowing, endorphins pumping. It was fantastic! I would leave the gym every day having worked hard but still ready for anything.

So, what's the moral of this little story? Well, we don't all have access to a Mark sadly, or a gym, but that's not the point. The point is to take exercise even if you don't want to. Even taking a leisurely walk is enough. I have pledged to myself to do at least one physical activity per day, whether it be lifting weights, walking outside (swimming in summer), tennis or just about anything (showering doesn't count). And if there's one thing about doing exercise, it's that you never regret doing it. I'd be a fully-fledged and overweight couch potato now if I hadn't just started to get active. I am gradually losing my stubborn cancer weight and starting to feel good again.

Deb’s Challenge

Out of the blue I was diagnosed with a brain tumor. A sore left eye led to an MRI which revealed a large tumor wrapped around my optic nerve, carotid artery, growing from the front of my forehead to the back of my head. Described to me like ivy, it was invasive and spreading its tentacles in the tiny spaces in my brain.

Having experienced few symptoms, I was shell shocked by the diagnosis, surgery and recovery that lay ahead. Right from the start my husband Grant and I decided to take a team approach – to do this together from start to finish. To be open with family and friends about the diagnosis and to hopefully remove some mystery and fear about brain surgery.

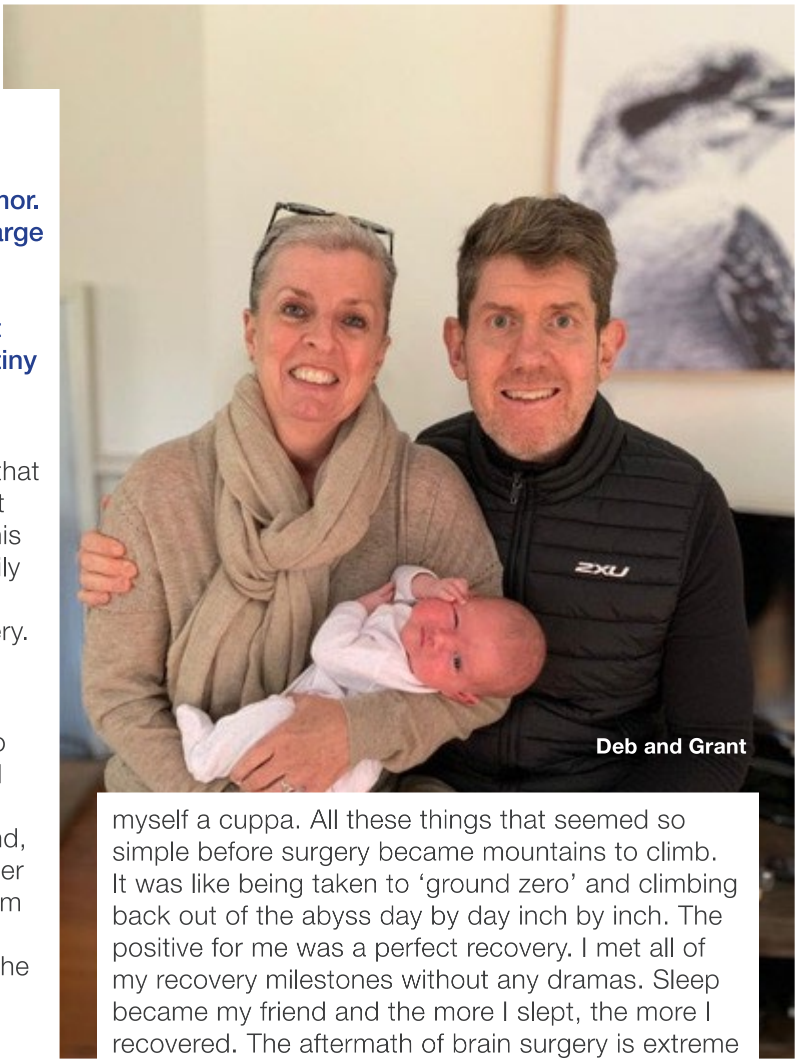
I was fortunate to have family, friends and my GP’s husband working in the medical field of neurosurgery, so with their guidance I was able to make an informed decision as to who, where and when we would tackle this head on (excuse the pun!). With the unwavering support of my husband, family and friends, I put my personal affairs in order and on the 25th March 2020, a neurosurgical team led by Dr Nazzi Assaad performed 13 hours of surgery at Macquarie University Hospital right in the midst of Sydney’s COVID lockdown.

It was with great anxiety and apprehension that I faced the biggest challenge of my life. Many questions swirled around in my mind – would I get through the surgery and if I did would I be impaired in any way? Would I be able to walk, talk and experience life as I had in the past? Would my thinking or cognition be impaired in any way? I had such faith in my medical team that I knew they would do their best to get a positive outcome for me.

Waking in intensive care six days later with a very funky hairstyle, and 50 staples in my head I knew it was up to my body to let the recovery unfold and to put my trust into those around me to guide my recovery. I felt no pain just some nerve discomfort from the staples in my skull – in fact the pain was much less than I anticipated. Ice cream, porridge and cheese sandwiches became my staple diet during my recovery.

The histopathology revealed my tumor to be a Grade 1 Meningioma – a large benign tumor 4cm x 3cm x 3cm. I felt such relief and gratitude.

After two weeks of recovery in hospital I was finally home in my own bed and once again united with my two mini dachshunds. Learning to walk, talk, think and do simple self-care tasks was challenging and took time and patience. Gradually day by day I noticed that things were becoming easier – I could walk further on my own, watch a little TV and make myself a cuppa. All these things that seemed so simple before surgery became mountains to climb. It was like being taken to ‘ground zero’ and climbing back out of the abyss day by day inch by inch. The positive for me was a perfect recovery. I met all of my recovery milestones without any dramas. Sleep became my friend and the more I slept, the more I recovered. The aftermath of brain surgery is extreme fatigue – some days were good - others more challenging but I always played the long game and kept my focus on the horizon where full recovery was my goal.


Deb and Grant

My husband Grant, my dearest friend Nic and so many others held my hand and were cheering for my full recovery from the sidelines. This gave me strength and focus to keep going.

After six months of recovery I was weaned off the medications that prevented seizures and swelling of the brain. This was a milestone for me as I felt I was beginning to get back to ‘normal’ life. Being given the ok to drive 10 months into my recovery was another red letter day. After being so dependent on others I was finally becoming independent again.

12 months post op I opened a homewares store in Laguna NSW with my business partner and friend Chantal. Her incredible belief in me was the best rehab I could have! Life is better post brain tumor – it has given me the gifts of insight, courage and patience. Things that seemed a big deal before are now just a small ‘glitch’ on the radar of life!

My hair is growing back and apart from losing my taste, smell and a small part of my peripheral vision I am back to normal. An annual review by my neurosurgeon will be part of my health care for the next 5 years. Fingers crossed I go from strength to strength.

Racing for BTAA

Nathan Draper

Kevin Le Poidevin

Darrell ‘Daz” Greig

Port Stephens based offshore sailor Kevin Le Poidevin and his Adelaide based co-skipper Darrell ‘Daz’ Greig, are two long serving Air Force aviators preparing their 1983 Sigma 36 yacht *Rogue Wave*, for the iconic **2021 Rolex Sydney Hobart Yacht Race**. They will race in the inaugural, and extremely challenging, double handed division. The pair plan to better their 2019 race time and arrive before New Years Eve. They are racing to support charity and their Canberra based Air Force mate, Nathan “Bullet” Draper.

Catherine Hindson, Committee Chair (ACT) for **Brain Tumour Alliance Australia** is delighted that Kevin is supporting the organisation. *“When Kevin first contacted us were amazed by his incredible and inspirational adventure. The opportunity for national and international exposure will assist in raising community awareness of brain cancers and the work BTAA do assisting patients and families impacted by brain cancer.”*

The two serving Air Force aviators are digging deep for their Air Force aviator mate Nathan ‘Bullet’ Draper, who in 2019 was diagnosed with glioblastoma multiforme (GBM), the most aggressive type of cancer that begins within the brain. Kevin clearly recalls the day he heard the heartbreaking news. *“I just couldn’t comprehend why Nathan. He is young, fit and healthy and an absolute ball of energy. In 2015 we were both posted to the United States on the F-35 Lightning fast-jet program. Nathan’s outstanding contribution was pivotal to the successful introduction of Australia’s F-35 aircraft. Every time you see or hear an F-35 aircraft, remember as you watch in awe to thank your mate Bullet”*

Kevin had just returned from his USA posting where his wife Narrelle had been volunteering with the local ladies at *Yarn Crafters* crocheting hundreds of soft wool beanies for cancer patients and children in need. Little did they know their mate Bullet would soon require beanie support.

“During his amazing journey through post-op recovery, I asked Bullet if he would like me to raise awareness and funds for his preferred charity through my sailing. Nathan told me of the great work by Brain Tumour Alliance Australia in not only supporting the patients, but also the family, caregivers and loved ones. After looking through the BTAA website and the members personal stories, I knew this was an organisation that cares” said Kevin.

PROUD SUPPORTER OF
SOLDIER ON

About: 2021 Rolex Sydney Hobart Yacht Race is a 628 nautical mile race from Sydney Harbour to Battery Point Hobart, starting at 1300 hours on Boxing Day 26 December 2021. Follow the link to the event website for more information to enable you to track the progress of Rogue Wave.

https://www.rolexsydneyhobart.com

About: 2023/24 Global Solo Challenge is a 26,000 nautical mile circumnavigation sailing singlehanded, non-stop and unassisted in a 40 foot yacht from Spain. Follow the link to the event website for more information where you will find my Blog page and fundraising links to Brain Tumour Alliance Australia and Soldier On.

https://globalsolochallenge.com

HOW YOU CAN SUPPORT

BRAIN TUMOUR ALLIANCE AUSTRALIA

https://www.justgiving.com/fundraising/kev-n-daz-2021-sydney-hobart-rogue-wave-for-bullet

SOLDIER ON

https://fundraise.soldieron.org.au/fundraisers/kevinlepoidevin/racing-for-our-mates

Rogue Racing

http://rogueracing1.blogspot.com

https://www.facebook.com/RogueRavings

Nathan "Bullet" Draper story (unaltered and from the heart):

"A cancer diagnosis for any type of cancer, provokes so many question for friends, and especially family and care givers. I recall sitting in that hospital room on the 8th Oct 2019 recovering from Brain surgery, and my Neurosurgeon giving my wife and I the outcome of pathology results. 'I am really sorry but you have a brain cancer that is called a Glioblastoma Multiforme, grade 4'. The first thing I wanted to know was what does that mean and how long (grade 4 and cancer is never a good thing), her answer was short 'on average you have 12-16 months'.

I asked her to help me get to three years so that I could see my eldest out of University, and my youngest son through Yr 12. In an instant I had given up on the loving embrace of a grandchild. She looked me in the eye and with empathy said that she will get the brain cancer specialist nurse to come and talk to us, we were introduced to BTAA in the next hours.

Cancer provokes many questions especially an insidious type, as I have. While it was not immediate, and I had no special 'moment' happen, I did come to terms with the situation. I just thought that I owed it to my family first, but also the many people who came forward in support of my situation to get up every day and face whatever challenge happened on any given day. Being able to walk again was the first of many. Getting to Radiation therapy a month after surgery, 12 months of chemotherapy, and then back to work again. All the while I had the support of two amazing organisations in helping me, and they were BTAA and Soldier On, both in Canberra. And I cannot forget also my employer, the Air Force.

Being able to get with people who are dealing with the stuff that you are dealing with is comforting in a strange way. I never saw myself as a group type person. I also never saw myself being sick either. When sitting in hospital, oncology, or palliative care waiting rooms, I recall looking around thinking these are not my people. I am a motorcyclist, an avid cyclist, I like the outdoors, they are my people. But it was different with the local group at BTAA, in them I also found a group of normal people affected in different ways by Brain Cancer or Tumours. And this I have learnt as well, those people in the waiting rooms are just like you and I, we have just been dealt with a different hand to play.

I also cannot speak highly enough of my local Soldier On team. I attended and still do attend activities with them. While undergoing chemotherapy it was nice to go for a fortnightly walk when I could get out of the house and just be with nice people. They are very supportive no matter what your Defence background and do so much unnoticed work for serving military families and the Veterans community at large.

I am beyond happy; and am very lucky to be given a couple of more years to embrace what each day brings. I don't consider that I have a lot to complain about, even though I am in the situation that I am. I am really proud to have mates who even think about doing this type of stuff and involve me and the wider brain cancer community. A big thanks to Kev and Daz who was on my apprentice intake when we joined, for helping out! "

Nathan confronts his brain cancer by expressing his thoughts, trials and feelings through his 'warts and all' public journal called The Tumour Trip. Follow the link to read Nathan's confronting, but also educational story. Read more at: https://bu11itt.wordpress.com

Ankit Walks For His Brother

60km Walk-Cut-n-Dye 4 Brain Tumour Support

Ankit writes; "My Brother Ishan was the perfect older brother - part pride of my family and a beautiful soul on his way to serving the community as a doctor - part annoyance who was always one-upping me. But in late 2010 Ishan was diagnosed with multiple late stage Glioblastoma (GBM). Considered the deadliest form of cancer, GBM is an aggressively lethal brain tumour that is often diagnosed late and robs patients of their central nervous system. Having valiantly fought GBM through three operations and rounds of chemotherapy Ishan must have decided he was bored of mentoring me, so on the 5th September 2012 surrounded by his family Ishan set-off on his next adventure.

In Ishan's memory and in solidarity with current brain tumor patients and families I am fundraising for a charity that supports brain tumour patients and their carers, I will be walking 60kms over each remaining Sunday in September (12/09, 19/09, 26/09), walking over 20kms on each Sunday! I will also be buzz-cutting and dying my hair blond at the end of September!

The money raised will support the Brain Tumour Alliance Australia (BTAA).

Thank you from the bottom of my heart,
Ankit

Update: With your generous support we have blown past 1 stretch goal and have almost reached $6,000!!

Here is a link to the fundraiser if you would like to share it with anyone you know: https://gofund.me/2b83d541

Brain Tumour National Advocacy Client Support Resources & Advocacy

Starts November 1 2021

EQUIPPING PATIENTS AND CARERS WITH SOUND ADVICE, INFORMATION AND PRACTICAL SUPPORT IS VERY IMPORTANT

From our experience in the brain cancer community one of the primary gaps for patients and families is the availability of sound advice and quality resources.

For many families and individuals, suddenly dealing with the challenges of brain cancer can become very overwhelming and they do not know where to turn to get a better understanding of the complexities of the disease and what resources or government services are available to them.

At Peace of Mind we are extremely passionate about collaborating with other organisations to help assist our clients.

- **Information**
- **Advice**
- **Local support services**
- **Contacts**
- **NDIS**
- **Centrelink**
- **'The Survivorship Diary'**

If you require the services above or are seeking services for your specific needs, we would love to hear how we can help.

To find out more information about support services that may be available to you, visit: https://bit.ly/pomfcbcf

Fiona Can Guide on NDIS Issues

Fiona Hassman is the newest recruit to the National Advocacy Service

December 2018 started out like any other month of the year. My partner Geoff was run off his feet getting work done before the Christmas break for his electrical business. I was working in relocations (as I had for 35 years) assisting people move seamlessly within Australia and across the world. Both of us are hard workers, we put everything we had into every single day. Our blended family meant there were seven of us to contend with, with 5 kids ages ranging from 15 to 22.

And then one quiet afternoon, on New Year's Eve, 2018 – Geoff couldn't talk properly. Without us knowing at that point, it was that second, that single moment, that was to become the instant that our world turned on its head.

In the coming weeks, Geoff was diagnosed with glioblastoma, a deadly and aggressive form of brain cancer. We were given the gut-wrenching and heart-breaking news that he would likely survive less than 12-14 months. He was 43 years young. His tumour was determined as inoperable, with medical treatment the only life extending option available.

Neither of us could work, Geoff was unable to continue working as an electrician and due to the intense quantity of medical appointments and associated recovery periods – neither was I. That single instant, on New Year's Eve turned Geoff into an individual with disabilities and me into a full-time carer.

The navigation surrounding assistance and information was ludicrously difficult. Approaching Centrelink for financial assistance was four months of begging and drowning in paperwork; trying to close his business, terminate our staff, my own work needing to shuffle someone else into my position to make do. We both struggled through the practical running of our home and lives in the initial months of diagnosis. It took me hours upon hours of researching to find what would help, what would assist him to be the best person he could be – for whatever time he was here.

In July 2020, I was approached by Peace of Mind Foundation to discuss my role in advocacy for Geoff and my work to gain him access to the National Disability Insurance Scheme (NDIS) in Australia. Sadly, this is a highly recognised need amongst many families, due to the regular rejections received in response to their NDIS applications.

I started working in a voluntary role, coaching and guiding other families through the process. I have successfully supported numerous families in receiving substantial funding packages through the NDIS. My heart and soul are overflowing with happiness, knowing what these families will be able to achieve with this funding.

In recent months, discussions have commenced for me to start working part time in an extended advocacy role for brain cancer families. I am beyond excited to transition my career into this position.

Whilst Geoff miraculously continues to survive this deadly disease, I do hold fast in my opinion that a good percentage of his survival rate is due to the life we have been able to maintain, and the support that has enabled this to happen. Being able to recognise the needs, and what is appropriate to support not only him, but our family, has been my drive for the past 2 years. It brings me joy to be able to provide this same level of advocacy, guidance and empowerment to our brain cancer community, and families alike.

It is with utmost pleasure that I head into this new journey with Peace of Mind Foundation, made possible by Cure Brain Cancer Foundation.


Geoff and Fiona

My Cancer Journey

Philomena O'Neil

My cancer journey has been a journey of tears and many times a journey of fears. The road along the way has been challenging as I found myself navigating over pot holes and rough edges. It has been a positive journey in so many ways as well.

A 10% or 20% rate of survival is not zero percent so there is always hope. I was given the worst prognosis with a zero percent chance of surviving but I continued to handle the things that came my way. I am four and a half years on with no progression so far.

I am not battling or fighting this disease as I have chosen to heal, recover and survive this journey. No TV news programs for me just programs that make me feel good. We are not travelling in reverse but moving forward on a cloud of hopes and dreams. I have taught myself to be a cancer survivor and I have learnt to thrive and survive through positive affirmations, positive visualizations and laughter.

Along the way one of my clinicians told me, "Get your hands dirty, be in touch with the earth", so I planted a small vegetable garden, that still delights me today. "Take up pottery and submerge your fingers in play dough it's all good for the senses", he confirmed. So, I took up pottery until the back seat of my car was piled high with failed pottery pieces wrapped in newspaper. It was a lot more difficult than I had imagined but I persevered. Eventually a few pieces emerged from the kiln that looked half respectable. They were given to any unsuspecting victim who was having a birthday!

No news programs for me any longer, just programs that make me feel good. Each night before we go to bed Ollie our toy poodle sits like an Egyptian Sphinx at the end of our bed waiting for me to put Escape to The Country on. The vistas of the English country side are always a delight to watch and are calming.

On one of my hospital visits when I was lying in a hospital bed late at night, cold, alone and feeling miserable, a nurse entered my room and asked if I would like a warm blanket placed over me. Yes, Cabrini Hospital in Melbourne has warm blankets!

That warm blanket was so welcoming and comforting.

Now and then when my thoughts get the better of me and I find myself having a blue day, I rest, then visualized the universe wrapping a warm blanket around me to comfort and heal me.

This disease is tenacious but don't let it define who you are as a person because you are more than that and can in time offer hope to others.

Be inspirational with your thoughts and may the universe heal and guide us through the rest of our cancer journey together

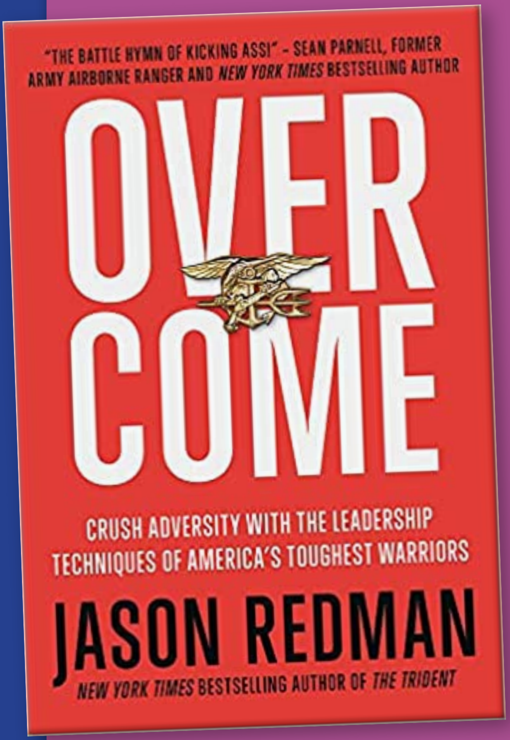
Philomena is a member of the Sydney Support Group

Ollie the toy poodle

NATHAN'S BOOK REVIEW

OVERCOME: CRUSH ADVERSITY WITH THE LEADERSHIP TECHNIQUES OF AMERICA'S TOUGHEST WARRIORS

BY JASON REDMAN



What a book! There is no doubt that there is truth in the saying that 'there are only two certainties in life, death and taxes'. However in this book, Overcome, by Jason Redman, he introduces another absolute guarantee in the way of those life events, best described as ambushes. His use of the term ambush comes from his background in the military as a retired Navy Seal.

Redman describes numerous types of these life events in the form of serious injuries, disability, personal tragedy, and importantly to folks reading this review, you'll be dealing with serious life threatening illness. How does he know this? Why is he qualified to talk about these events called ambushes? Because when he was in Iraq he was caught in an ambush that left him awfully disfigured, and almost dead on the battlefield.

Indeed the medical team who dragged him from the ambush sight in a medivac helicopter do not know how he survived, the treating medical teams that followed also do not know. He lost so much blood he should not have survived. After a task he was leading his team out and was caught in the open, no cover and a machine gun opened up. Taking rounds to the left arm and through the face. His left arm was almost severed so severe were the wounds that he sustained.

On return to the US to undergo multiple surgeries so that he could retain his arm and many facial re-constructive surgeries he found himself with one of two options, depression or working out how to just plain deal with it and live. He chose the latter, and ensured that he informed people who came to visit exactly that. I won't spoil it and tell you what he wrote on the sign that he had his wife stick to the door of his hospital room, but it is the crux of his mental attitude and the start of him not just rebuilding his life but working out who he is, and eventually to go on to assist others.

His mantra is that we will all face a challenge, some bigger than others. Some life threatening, and others just standard stuff that will rock our path enough to get you off balance, and facing those same two options. He describes these events as a life ambush. His advice is pretty simple, and he offers the same advice that military teams do when facing an ambush. When you get ambushed there is one thing you need to do above all to be able to gather yourself, and that is get off the X, where X marks the ambush site on a map.

You get up fast, look forward and move. No he doesn't underestimate your issue. Nor what you are going through at that time in your life. But in using his own experiences and life events not just health but life issues. In his dealing with veterans who faced serious injuries, to PTSD, Redman offers advice from someone who has been there, who has had to dig deep, look to his family for not just grounding but support.

I was asked this week by a friend whose husband has the same GBM diagnosis as I do, and has just finished radiation, and is back in hospital going through a really rough time, "how do you get back up? How can you even be positive, let alone stay positive?" I have read a lot of books on this stuff since my own diagnosis two years ago (yesterday). And I can agree with Redman, get off the X. Look to tomorrow, it will always be a better day, and even if it isn't you have the opportunity to make it so. I said that there will always be someone worse off than you.

In reading this book, I realised that even though my outlook (medically) sort of sucks, I am lucky. Because there is always someone doing it tougher than me. You just need to be looking up, to get off that X. Not staying in the same place that is getting you down. I am not surprised it is a best seller, nor that Redman speaks in the corporate world.

This book is a highly recommended read.

Nathan Draper

Hi I'm Nathan, Living with GBM4 since Oct19. The tumor has been de-bulked, Radiated and Chemo'd. I love family, getting to the gym, riding my bikes, and reading stuff to keep me going, which I love to share. You can check my blog out here: www.bu11itt.wordpress.com

Head to the Hill

Diane Dunn

Event Postponed

Inspired by an event held in Washington DC, called "Head to the Hill" BTAA members have been actively planning a similar event in Australia. Hoping to coincide with International Brain Tumour awareness month (IBTAM) in November, we set about planning an event which would raise awareness generally, advocate to the policymakers directly to inform them of the needs of the brain tumour community. As we envisage this event to be held annually, it will also serve as a reminder to the public and politicians that survival rates have not changed in 25 years, and set out ways we might seek to change that!

We hit our first hurdle when we learned that Parliament would not be sitting in November, and therefore we could not be able to achieve one of of goals of the event - to meet with politicians. With Parliament sitting in the second week of October, we decided we would hold the event on the 20th October in recognition of the coming IBTAM.

Much planning and work has been achieved since this idea was first born. We have successfully:-

- Secured meetings with both Minister Hunt and Shadow Minister Butler.
- Made application to seek all relevant permissions to stage the event
- Liaised with publicity and PR experts to understand how best to achieve publicity and coverage of the event;
- Commissioned the design of a logo to represent the event;
- Agreed on a plan to install (temporarily) a set of white chairs with grey corflute ribbons to represent the number of deaths in one year attributable to brain cancer deaths;
- Outlined a plan to have speakers at the event both representing the point of view of patients and also medical speakers.
- Obtained quotes for the provision of services such as hiring chairs, producing corflute ribbons

Unfortunately, as the date approached it was becoming evident that Covid restrictions might prevent the event being staged - due to both preventing gathering in the ACT, but also preventing our members and families from attending the event.

So we have decided not to entirely waste our efforts so far, and make the call early that we will postpone the event until May of next year - to coincide with "Go grey in May" - with the proviso of course that Parliament is sitting at some point in May.

The Washington event has both grown in numbers and evolved over the years and the event not only allows the brain tumour community to meet and share their stories, the organisers now offer training to interested participants on how to participate in congressional meetings, how to advocate for change effectively, social media tips, provide assistance on how to turn your impactful story into an effective advocacy tool.

We are so excited about the prospects and opportunities this event may bring us in the future. Stay tuned to future newsletters for announcements about the date in 2022. If you have any ideas to share or would like to help with any aspect of organisation please make contact and let's chat!!

ENGAGE to Support Childhood Brain Tumour Survivors

‘Engage’ is an initiative of the Kids Cancer Centre, Sydney Children’s Hospital and the Behavioural Sciences Unit, UNSW Medicine & Health. The Engage program supports survivors who were diagnosed with low-grade glioma during childhood by providing distance-delivered survivorship care.

Professor Claire Wakefield

If you’re a survivor of childhood brain cancer, you probably already know that surviving doesn’t necessarily mean having perfect health. Most survivors will develop “late effects” as a result of their cancer and its treatment. This might include neurological issues, problems with hormones, heart disease, weight gain, and anxiety or depression. Navigating the health system to get the care you need after cancer treatment can also be a challenge.

Engage Brain is a new program designed by a team of paediatric oncologists at Sydney Children’s Hospital. It’s aim is to help survivors feel more confident to get the care they need and improve their health in the long term.

UNSW Professor Claire Wakefield and her team at UNSW are leading a program to help childhood brain cancer survivors improve their confidence, manage their health and improve their quality of life. The trial to roll out and test the effectiveness of the program – called Re-engage – was launched last month.

Funded by a $1.9 million grant from the Government’s Australian Brain Cancer Mission, part of the Medical Research Future Fund (MRFF), the program is part of a $9.9 million investment in brain cancer survivorship research announced by the Australian Government.

“Over 90 per cent of childhood brain cancer survivors have health problems after they finish cancer treatment, yet most Australian survivors are not receiving the follow-up care they need to manage these problems,” Prof. Wakefield said.

“Re-engage is a distance-delivered program that offers survivors two nurse consultations and careful case review by an expert team. This means that survivors can access support no matter where they live. Our nurses create a care package for survivors which includes a summary of their care needs, a letter for their GP, and education about healthy lifestyles.”

Prof. Wakefield said the pilot study of Re-engage confirmed that the program significantly improved survivors’ confidence to manage their health. The pilot study was supported by The Kids’ Cancer Project, Cancer Council NSW, and Kids Cancer Alliance.

The next step in the research project – the Re-engage trial – is significantly larger and includes childhood brain cancer survivors treated at Sydney Children’s Hospital, Randwick, The Children’s Hospital at Westmead and Perth Children’s Hospital. The trial will evaluate the impact of Re-engage on survivors’ quality of life and their ability to self-manage their survivorship care. The trial also focusses on developing and testing a detailed implementation strategy so that Re-engage can be rapidly rolled out nationwide.

If you would like to take part, here’s what you can expect;

- The program is delivered remotely, so you don’t need to travel to the hospital.
- You will be asked to complete a Health Assessment survey and talk to a survivorship nurse about your current health.
- Your health information will be presented to a team of specialists who will make recommendations about the care you need.
- These recommendations will be summarised in a letter for your GP and yourself.
- The survivorship nurse will offer you a second appointment to ensure you understand the recommendations, troubleshoot any barriers to care and answer any questions.

Engage is now being offered to survivors of any age, who were diagnosed with a childhood brain cancer (<18 years), and who were treated at Sydney Children’s Hospital. We will soon open to survivors treated at Children’s Hospital Westmead and Perth Children’s Hospital.

Learn more about the Re-engage program, or to get involved, please visit: https://www.behaviouralsciencesunit.org/engage.html

For more information please view this short (2 minute) video https://youtu.be/OI5CK9-JH5Y

Or contact the Engage Brain team
Engage@unsw.edu.au
0466 576 442

The July Meningioma Patient Education Day

In late July this year The Brain Cancer Group (TBCG), in collaboration with the BTAA, hosted a virtual public forum on Meningioma to aid further understanding of this oft-neglected primary brain tumour. Initially the event was planned as an in person forum, but as COVID events unfolded arrangements were made to make it an online forum.

Clinicians from the multidisciplinary neuro-oncology team from Sydney's North Shore Campus presented aspects of care including neurosurgery, neuroradiology, nuclear medicine imaging and radiation therapy. Given the diverse natural history and presentation of meningiomas, an emphasis was placed on the importance of a co-ordinated approach to optimise care of patients with newly diagnosed or recurrent tumours. With excellent and improving control rates and survival, there is a demonstrated need to deliver interventions in a targeted and safe manner to minimise risks of late side-effects. Diagnostic approaches utilising MRI and PET scans were detailed to aid neurosurgeons and radiation oncologists in the treatment delivery.

The meeting was chaired by **Marina Kastelan**, Neuro-oncology Nurse Practitioner from The Brain Cancer Group; and questions submitted in advance from BTAA members, and the public allowed the clinicians to deliver presentations relevant to the needs of our community.

Dr Jonathon Parkinson - Neurosurgeon at Royal North Shore Hospital and North Shore Private Hospital detailed factors associated with the development of meningiomas and the high incidence in the general population. Issues affecting decision-making at time of initial diagnosis was discussed and the need for various surgical approaches given the varied manner in which these tumours appear in the brain.

Dr James Drummond – Neuroradiologist at Royal North Shore Hospital & North Shore Radiology and Chief Neuroradiologist for TBCG Imaging Laboratory described the imaging techniques that not only confirm diagnosis and aggressivity of tumours, but also how imaging guides the neurosurgical teams to determine the extent of meningioma infiltration and invasion.

Dr Geoff Schembri – Nuclear Medicine Physician @ Royal North Shore Hospital & North Shore Radiology expanded upon the exciting developments of targeted PET scan imaging that not only assists in mapping out the extent of tumour but also the potential to use these pharmaceuticals for a targeted radiation therapy approach. He reported some of the early data from the RNSH experience with the novel "Lutate" peptide receptor radionuclide therapy (PRRT), which uses these targeted pharmaceuticals and medical isotopes to deliver radiation directly to the tumour as an adjunct to standard treatment.

A/Prof Michael Back – Radiation oncologist from RNSH, Gosford Hospital and Genesis Care outlined the principles of sophisticated radiation therapy that apply to meningioma and the indications for treatment. An emphasis was placed on the patients with atypical meningioma and the importance of utilising the MRI and PET scan techniques to aid in targeting the radiation therapy. He described the importance of this planning approach with regards to minimising the late side-effects of treatment given the excellent survival outcomes now being experienced by our patients.

Multidisciplinary care services on the North Shore were described including the:

Sydney Meningioma Clinic opening at the GenesisCare North Shore Health Hub in September; and the TBCG supportive care initiative for patients with meningothelial tumours funded through the 2019 Laugh Your Head Off fundraiser.

TBCG and BTAA were encouraged by the success of this initial collaborative education forum and are developing more specific programmes for both patients and clinicians in 2022.

Thanks to Dennis Tritaris from ORANA Communications who organised the technical aspects of the Education Forum.

Dennis Tritaris of ORAMA Communications set up the webinar

Deb Harrod – local luminary – behind a wonderful fundraising event in the Wollombi Valley

On Friday June 18th the local community of Laguna and Wollombi Valley came together for an electric fundraiser at the GNTP [Great Northern Trading Post] – all the inspiration of Deb Harrod - a local firecracker.

Motivated by her own brain tumour story, Deb wanted to raise funds for BTAA, knowing how vital resources are for this national not for profit support organisation aspiring to tend to the multiple needs of those facing a brain tumour journey. Family and friends as well as the tumour sufferers themselves.

Deb has defeated her brain tumour and while others can be so fortunate, many are not. There are 120 different types of brain tumour, and to be diagnosed with one – in any guise – is a devastating experience.

Deb Harrod

The brain tumour experience has not stopped Deb for a moment.
She is co-owner with Chantal Roger - of a delightful boutique in Laguna – a venue all the locals find irresistible.
She also teaches yoga in Sydney, when COVID allows.

On the night, we were all treated to a banquet cooked up for the occasion by Rosa Marsh the co-owner of GNTP who spoiled the guests with an array of mouth-watering dishes - on an evening when warm, tasty food was of the essence. Rosa's staff were outstanding in delivering hot savoury food to all patrons in record time while in the background there was a silent auction to bid on. Garry Musgrove, friend and Principal of Musgrove Realty pictured below was chief auctioneer – with items generously donated by locals and the generous-hearted from further afield. There was also a live auction which was great fun. And the evening would not have been complete without the dynamic music brought to us live by The Well-Dressed Gentlemen. The dance floor was pumping.

This writer had departed by 10.30 but rumour suggests the party went on well past 1.00am, and yet the next morning everything at GNTP was pristine, and smiles on all faces were as broad as ever. Including Deb's, Chantal's and Rosa's.

The takings for the evening approximate $10,000. This includes Rosa Marsh giving 10% of the dinner costs, and all the incredible generosity of the local community in providing items for the two auctions and then bidding on them too.

There is whispering down the local corridors that we may repeat this enterprise in our valley next year. Stand by.

BTAA thanks everyone.

Alice Parsons
NSW Representative BTAA Committee

13th COGNO ANNUAL SCIENTIFIC MEETING (Virtual)

Brain Cancer 2021: Concepts to Cure

Sunday 24th - Tuesday 26th October 2021

INTERNATIONAL SPEAKERS

PROF NINO CHIOCCA

MD PhD FAANS

PROF GELAREH ZADEH

MD PhD FRCSC FAANS

PROF DAVID N. LOUIS

MD

PROF MICHAEL JENKINSON

MD PhD FRCS

Stay posted for further updates, or email ctc.cognoasm@sydney.edu.au to join our mailing list.

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FOR NEURO-ONCOLOGY

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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