



# International Brain Tumour Awareness Week 2015

25-31 OCTOBER

This newsletter was produced with the assistance of funds from Mel Goes Grey in May.



## LETTER FROM THE CHAIR

## INSIDE THIS ISSUE

- Letter from the Chair
- Therapy news from ASCO
- BTAA's new recruits
- Emotional side effects
- Carers are key team members
- Bob and Anita's Grand Tour
- Funding assistance available for events
- Anna 2015 Conference
- Nicola Sheenan's training tips
- Sharon's secondary B.T. journey
- Calendar of Events
- Thanks
- Useful Links

### This issue marks International Brain Tumour Awareness Week which falls on 25 – 31 October 2015.

Read about some of the activities planned to mark this week, including a great forum in **Brisbane on 22 October 2015**.

**BTAA** and the **Cancer Council Queensland (CCQ)** are co-hosting the **BTAA 3rd National Summit**, a lunch and special educational forum at the CCQ offices from 12 noon to 3 pm. The lunch features international speaker **Professor Martin van den Bent**. Read more and register for this event on the BTAA events page – [www.btaa.org.au/events](http://www.btaa.org.au/events). Find the green ticket to book!

BTAA is the umbrella organisation providing a strong national consumer voice for brain tumour patients, carers and families. BTAA's focus is on support and advocacy.

Several BTAA members will be staying on after the BTAA Summit to attend the **Cooperative Trials Group for Neuro-Oncology (COGNO) Annual Scientific Meeting 2015** in Brisbane on 24 to 24 October 2015. See [www.cogno.org.au](http://www.cogno.org.au) for more information on this important meeting.

**Susan Pitt** from BTAA, together with **Barrie Littlefield** from Cure Brain Cancer Foundation, will represent Australia at the **2nd International Brain Tumour Alliance Summit** on 26-27 October in Sitges, Spain. There will be over 60 people from 27 countries. It should be a great opportunity for networking, sharing best practice and hopefully picking up some new skills and a greater understanding of the various issues in the international brain tumour patient and caregiver community.



*BTAA and the Cancer Council Queensland (CCQ) are co-hosting the BTAA 3rd National Summit*



*Professor Martin van den Bent*

CONTINUED PAGE 2

LETTER FROM THE CHAIR

CONTINUED FROM PAGE 1

A great start to International Brain Tumour Awareness Week. Susan will be facilitating a workshop on peer/patient support and hopes to bring back many new ideas from fellow travellers.

We know that many of you find solace and support from social media groups. One such group is the **Livewire – Starlight Foundation** social media group - a special online community designed just for young people living with a serious illness, chronic health conditions or disability. It is a safe online space where members can connect and share experiences what they are going through with others who understand. See [www.livewire.org.au](http://www.livewire.org.au)

In this issue, we present two great articles by clinical psychologist **Katharine Hodgkinson**. We also feature some great photos of our supporters who raise awareness and/or funds to help us. Read about **Bob and Anita Berghout's** great work on tour, raising awareness in regional areas. And about events held by **Mel Johnson** in Bathurst, Barry Walls near Geelong, **Susan and Mark Dalliston** and their supporters. Also thanks to those who crocheted, knitted or sewed to help BTAA.

We also feature some photos of our supporters at a range of amazing fundraising events that help BTAA provide information packs for both children and adults diagnosed with brain tumours.

Thanks to all those who have donated time and/or money to BTAA and to raise awareness. Read about **Anita and Bob Berghout's** initiative on this issue.

I am thrilled to announce **Mel Johnson** of Bathurst presented with a very special certificate at **Susan and Mark Dalliston's** Ribbons and Cranes dinner. Mel travelled from Bathurst to Canberra to receive the certificate from **Mark Dalliston**, BTAA's Vice Secretary, at his 50th party.

We love the approach of another Mel - **Mel Tempest** of Bathurst - who has run three events this year for BTAA – including her 30th wedding anniversary, her 50th birthday, a dinner and a stall. Mel runs fitness classes and she said when she turned up the staff got the members involved and they were all wearing beanies/pins and hats. Who all got extremely hot during the class!

On that note – a huge thanks to **Carrie Bickmore**. What a great boost she gave us all.

**Susan Pitt,**  
Chair, BTAA



Incoming BTAA Chair Susan Pitt receives a cheque from Mark Dalliston from the Ribbons and Cranes fund raiser. Thanks Mark and Susan Dalliston



Mel and Peter Johnson and family



Catherine and Bill Hindson shows the BTAA newsletter to the Mayor of Bathurst, Cr Gary Rush



## BTAA's new recruits

At our Annual General Meeting on 27 September we farewelled three stalwarts from our volunteer committee including founding Chair **Matthew Pitt**, founding Secretary **Denis Strangman** and Vice Chair **Mary Anne Rosier**.

All three remain active members and ready to support BTAA as special advisers and on our new subcommittees. Thank you each for your amazing contributions. Denis won an Award of Member of the Order of Australia (AM).

Thanks also to outgoing Committee member **Anita Berghout**. Anita continues her awareness-raising work with the help of husband Bob. Read about their work on their travels in this issue.

We have some exciting new talent on the BTAA committee. Firstly a big welcome to **Janet Micallef** from Melbourne, **Julia Robertson** from Brisbane, **Jennifer Brodie** from Goulburn, **Philip Steel** and **Nicola Sheehan** from Canberra. These four dynamos are all willing to work to support others, using their experiences gained after the diagnosis and treatment of a brain tumour.

Philip volunteers at BTAA's desk in the SHOUT Office in Pearce, ACT as our administrative officer.

We are also pleased to welcome **Diana Andrew** from Perth. Diana supported her late husband and now volunteers at the Harry Perkins Medical Research Institute and is a Research Panel Consumer Advocate for the Cancer Council WA.

Thanks also to **Tricia Berman**, BTAA's new Public Officer and Assistant Secretary. Tricia will keep our red tape in shape.

BTAA will be setting up some subcommittees to bring more resources to our important work – support, advocacy, education and advocacy for both adults and children impacted by brain tumours. Email [btaa@shout.org.au](mailto:btaa@shout.org.au) if you would like to hear more about the volunteering opportunities with BTAA. We particularly need a representative in Tasmania to help our youth ambassador **Jordan Cowen** represent BTAA.

**Read more about the new committee on our website under Who we are/ our people.**



*Denis Strangman AM received his award in June 2015 for services to the brain tumour community. Thanks Denis.*

## Therapy news from ASCO 2015

BTAA's Matt Pitt reported on the American Society of Oncology 2015 meeting in Chicago in the July e-news sent to over 1,700 subscribers. See <http://www.btaa.org.au/news>.

In addition to the information in this e-news Matt said the biggest news was discussion on whether a subset of low-grade glioma patients has unrecognised glioma and should receive concurrent radio chemotherapy as per the current standard protocol for grade III and 1Vs.

International neuropathologists consider the WHO Grade I, II, III, IV classification scheme could be better classified as Type 1, Type 2, Type 3 gliomas where the biomarker Isocitrate Dehydrogenase (IDH) enzymes status is the key prognostic marker used to guide treatment.

This prognostic has significant implications for Australia will need to move to the routine genetic testing of tumours for biomarkers in gliomas as well as the parameters for funding models for reimbursement.

Another issue what the discussion on which of the two standard

chemotherapies were the superior protocol for lower grade and grade III tumours.

In the next 12 months, BTAA will explore the Australian health system and the practice of genetic testing for biomarkers including IDH and 1p19q for glioma. We are interested in knowing – who does it routinely or on request, how much it costs, who pays (the patient or the hospital), what is needed to increase the update of these tests.

**Email [btaa@shout.org.au](mailto:btaa@shout.org.au) if you are a health professional who would like to contribute to this discussion.**



## Emotional side effects

By Dr Katharine Hodgkinson

**The following article is about the emotional side effects of living with a brain tumour – for those with brain cancer, their carers and loved ones.**

People often say they will never forget the moment they first heard the word cancer. The diagnosis is a significant life crisis for most people, their families and loved ones. It is often a new and uncertain experience, a life-altering event.

There will be similarities in people’s experiences and responses, but there will also be differences depending upon the type of tumour, location and stage of disease, and course of treatment. There will also be differences in how people respond depending upon your unique life situation and how it affects your lifestyle, your hopes and dreams.

The intensity and demands of treatments can be so fast-paced and overwhelming, that the emotional aspects of well-being are not given time or attention. Some patients, families and carers may feel reluctant to discuss this area of their well-being. However, emotional responses can affect your quality of life - this is a really important area of your care.

A range of emotions is common for you and your loved ones - sadness, fear, anger, numbness and disbelief. All of these are completely normal feelings to experience and may fluctuate during treatment and care. You may find yourself worrying more, irritable, “on edge”, and struggling to sleep well. A loss of confidence in your health or loved one’s health and the constant waiting – waiting for doctors’ appointments, waiting for test results, waiting to see if the treatments have provided the hoped for responses – can be very stressful and unsettling. Symptoms of depression and anxiety are common, but help is available.

**State Cancer Councils are a very useful starting point for up-to-date information on the range of individual, telephone, face-to-face, group, peer and web-based support options available (see [www.cancer.org.au](http://www.cancer.org.au) or call 13 11 20).**

**Your General Practitioner will be able to advise you whether you are eligible for a Medicare GP Plan to refer you to a Clinical or Consulting Psychologist with expertise in helping those adjust to changes in their health and lifestyle.**

## Carers are key members of the care team.

By Dr Katharine Hodgkinson

**Carers provide crucial support to the person receiving treatment, be it practical, physical, emotional, personal or financial, but also need to support themselves.**

Loved ones and carers may share many of the same feelings and responses as the person receiving care. They may also feel pressure to 'keep it all together' while being 'strong and positive' – not always easy or possible! Carers and loved ones often find that their emotional responses fluctuate over the roller-coaster of care, just like those of the person receiving treatment. Some people find that dealing with their emotions and the emotional responses of those around them can be as challenging as the physical demands of treatment – and there's no instruction manual!

Everyone processes information and adjusts to information at a different pace, and it's common for people to feel like they're at loggerheads or not always 'on the same page'. Many people are very concerned about the impact of the illness on those around them, particularly children in their life. For a partner, child (including an adult child), parent or friend, they may feel helplessness as they watch on.

Keeping relationships as healthy as possible is vital to the physical and emotional health of all affected by a cancer diagnosis. Being able to talk, share support and learn about strategies that have helped others is important for everyone. Good communication and professional help can play an important role in helping people work together to support each other despite the challenges and individual differences in how we cope. A cancer diagnosis is a new and uncertain experience that involves thinking about strategies you may not have considered before. Many forms of support and help are available – seek and ask for help - it can make a difference.

So what help is available? Talk to your team - your doctors, nurses, Clinical Nurse Consultant, or social worker and ask about what services and supports are available. Your General Practitioner can be a great support - they will also be able to discuss a referral to a Clinical or Consulting Psychologist. Sometimes the thought of seeing someone new might seem like just another appointment, but it can be well worth the effort. Research evidence indicates that psychological interventions may improve the quality of life and well-being of those dealing with cancer. Other great sources of information and support include your State Cancer Council (see [www.cancer.org.au](http://www.cancer.org.au) or call 13 11 20) and Carers Australia ([www.carersaustralia.com.au](http://www.carersaustralia.com.au) or call 1800 242 636).



**Dr Katharine Hodgkinson leads a team of Clinical and Consulting Psychologists in Sydney providing strategies to patients, carers and families affected by a cancer diagnosis and other chronic health concerns.**  
Ph. 9453 3027, email: [info@headwayhealth.com.au](mailto:info@headwayhealth.com.au) or see [www.headwayhealth.com.au](http://www.headwayhealth.com.au)



*Mel Johnson speaks at her 2nd Mel Goes Grey in May at Bathurst Panthers*



*Mel receives the 'Sunflowers are Life Quilt'*



*The Mayor of Bathurst, Cr Gary Rush, speaks at Mel Goes Grey in May 2015*

## Bob and Anita's grand tour

By Bob and Anita Berghout

**BTAA committee member and BT patient Anita spread the word on their grand tour.**

Here we are in Melbourne, with two weeks to go to complete our three months adventure. Bob and I were determined to drop in on country hospitals on our journey and give, wherever we could, information about BTAA. Living in Newcastle, we had planned to go inland to Dubbo, but on the day we left the storm and rain was so horrendous that we decided to stick to the Highway to the Blue Mountains. We stayed in Blackheath and the next day the sun had arrived. The first town we came through which has a hospital was Bathurst, and the staff were very pleased to get the pamphlets and information about BTAA. To cut a long story short, we went to each hospital in the little outback towns we travelled through.

We went along the Murray River to Mildura (quite a few hospitals!), then to Broken Hill, then back to Quorn. We had an enjoyable detour for nearly a week in Arkaroola and then returned to Quorn so that we could go up the Stuart Highway. We visited the hospital in Coober Pedy (and enjoyed being in the town for a few days!), and then made our way to Alice Springs. Of course, we provided BTAA information to the Alice Springs hospital that is a large hospital. After also spending some time at Yulara, we drove back down South. We finally arrived in Wallaroo, where we also dropped off our flyers in the hospital.

Then Adelaide for two weeks, where we first met one of our BTAA friends, Andy Stokes, who gave us more leaflets as we had run out of our patch. We visited the four main hospitals in Adelaide to provide the BTAA information. Then Mt Gambier, Warrnambool, and Lorne. In Cobrico, we met up with a friend who is a physiotherapist specialising on brain injury or Brain Tumour affected people. She was delighted to know more about BTAA.

Everywhere, the staff were very happy to receive the BTAA information brochures and had information available for people in the country towns. They mentioned that while surgery happens in the bigger towns, there are many people with brain tumours living and getting follow-up treatment in smaller towns away from the major cities. So our next project? Small town hospitals in NSW!



Anita and Bob Berghout on their grand tour.



Bob and Anita on the way to another drop off.



## FOCUS ON SOCIAL MEDIA

Many of our supporters follow **Femme Henson's Facebook Page**. Femme started her Facebook page not long after her daughter Nicole was diagnosed with a GBM.

Femme told BTAA she started researching for support and answers into this dreadful disease. So it has been running for approximately 8/9 years and has just over 2,100 followers worldwide.

Femme says I often state if our page has supported or given hope to just one person then our job has accomplished what we set out to achieve. Her design skills are self taught over the years. Femme was herself diagnosed with a GBM earlier this year. Femme say their page has given her the strength, hope and positivity to never give up. Thanks Femme and Nicole for sharing your journey.

<https://www.facebook.com/Braincancer.gbm.support>  
awareness

## Funding assistance available for events/conferences

BTAA is interested in hearing from allied health professionals or researcher interested in funding assistance to attend national and international professional events. Grants of \$500 for national and \$1,500 for international events are available. Email [btaa@shout.org.au](mailto:btaa@shout.org.au)

## NATIONAL EVENTS

As mentioned above **COGNO 2015** takes place in Brisbane on 23 -24 October 2015. BTAA will be supporting the travel for some delegates to attend the BTAA Summit and COGNO 2015.

Planning is well underway for COGNO 2016. BTAA will be supporting Dr Danette Langbecker | Ph.D. BHlthSc(PubHlth) | NHMRC Early Career Research Fellow 's attendance at SNO 2016. Danette's travel will subsidise through the generosity of the family of the late Nicola Scott.

Read more about Danette's projects here: [http://eprints.qut.edu.au/view/person/Langbecker,\\_Danette.html](http://eprints.qut.edu.au/view/person/Langbecker,_Danette.html)

The **13th Asian Society for Neuro-Oncology (ASNO) Meeting/9th COGNO Annual Scientific Meeting** will be held in Sydney from 11 - 15 September 2016.

BTAA has grants of \$600 to support the attendance of allied health professionals from the interstate.

Save the Date: <http://www.cogno.org.au/docview.aspx?id=278>

BTAA is also pleased to be supporting the participation of **Associate Adjunct Professor Mary Lovely** Ph.D., RN, CNR at COGNO 2016.

## MAJOR INTERNATIONAL EVENTS

### SNO 2015

The 20th Annual Meeting of the Society for Neuro-Oncology will be from 19 – 22 November 2015 in San Antonio, Texas, USA.

### ISPNO 2016

12 – 15 June in Liverpool, UK. The 17th International Symposium on Paediatric Neuro-Oncology.

### ASCO 2016

3 – 7 June 2016 in Chicago, Illinois. The American Society of Clinical Oncology meeting.

### SNO 2016

17 – 20 November 2016 in Phoenix, Arizona, USA.

See more events and dates here: <http://theibta.org/events-and-conferences/>



Help BTAA during International Brain Tumour Awareness Week by organising a hat day. We have a kit we can mail you - Maybe Melbourne Cup Day can be a BTAA Hat Day?

[www.btaa.org.au/campaign/2/wear-a-hat-for-a-day](http://www.btaa.org.au/campaign/2/wear-a-hat-for-a-day)

## ANNA 2015 annual conference

By Marina Kastelan



Marina attended the 2015 Australasian Neuroscience Nurses Association (ANNA) 2015 Annual Conference in Brisbane with the support of a Nicola Scott educational grant facilitated by BTAA. The conference themed “The Jewel in the Crown - Keeping it safe in our hands” was held from the 9th-11th September 2015.

This year's theme of “Keeping it safe in our hands” looked at exploring the impact of patient care from a nursing, technological, pharmaceutical, medical, allied health and the patient & carers perspective.

Delegates from all areas of the Neurosciences field including neurosurgical, stroke, spinal, neurovascular and neuro-oncology came together from all Australian States and Internationally. Delegates from New Zealand and Indonesia joined the discussion

and presented papers. It was an excellent opportunity to network amongst like-minded colleagues who have a passion for the neurosciences field.

**Marina Kastelan (pictured left) at ANNA 2015 with the assistance of a BTAA educational grant.**

The two main presentations that stood out for me as a Neuro-Oncology Clinical Nurse Consultant and my specific interest in primary brain tumours was the discussion about the new molecular pathology of gliomas. The implication of this for future treatments by Medical Oncologist, Dr Paul Mainwaring, and Dr Rupal Javanth, Neurosurgeon based at the Princess Alexandra Hospital in Brisbane.

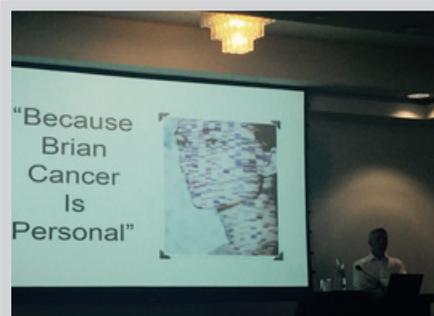
Dr Javanth spoke about subarachnoid haemorrhage, where a bleed occurs into the subarachnoid space within the brain, and the management and challenges of this. What was interesting to me here was the discussion of the long term neurocognitive and neurobehavioural issues that occur for these patients post haemorrhage. It is common to see patients who suffer impaired social adjustment, difficulty dealing with anger and personality changes and find it difficult to maintain employment. I found this relevant and thought provoking with the challenges with neuro cognition and memory I see in the glioma (primary brain tumour) population.

Dr Mainwaring is based at the ICON Cancer Centre at The Mater, Brisbane presented on new molecular pathology for gliomas, he had the audience excited about potential new pathways to create cell death in cancer cells, specifically gliomas, with the discussion around novel treatments with the use of PARP inhibitors and immunotherapy agents. Even though, new molecular testing is interesting and provides a new view on how we can potentially target tumour cells, safe agents or

new treatments are not available as yet; still, it is thought provoking and may one day lead to specific targeted treatments depending on tumour molecular pathology.

There were many interesting presentations on the two day conference; but one that really stood out for me with her ongoing drive and passion, was to hear the long road taken to develop a Neurosciences Association in Indonesia by Nurse, Enny Mulyatsih.

Enny discussed that whilst Australia has a great recognition for specialty nursing, such as Neurosciences, many parts of Asia, including Indonesia have struggled to meet basic nursing demands – it was amazing to see her achievements and drive to improve & support neuro specific education and competencies for nurses.



*Because Brain Cancer is Personal – Thought provoking spelling error?*

The **Australasian Neuroscience Nurses Association (ANNA) 2015 Annual Conference** supported and allowed presentations by many young and bright new nurses into the neurosciences field and continues to support those experienced with ongoing education, I was thankful to attend this conference with support of the Nicola Scott grant provided by BTAA.

**Thanks to Marina Kastelan, Neuro Oncology CNC, Sydney Neuro-Oncology Group, for this report.**

## Nicola Sheehan's training tips

By Nicola Sheehan

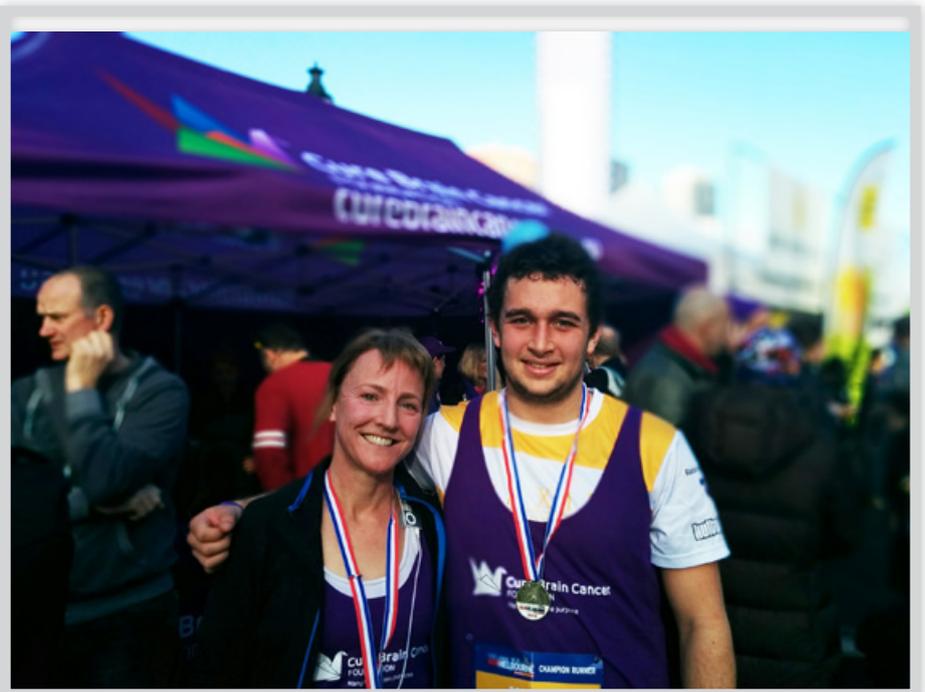
I was diagnosed with a low-grade astrocytoma 15 years ago and due to its diffuse nature and location in the parietal lobe my surgeon recommended radiation treatment then “watching and waiting” for the tumour to progress. At that time, I gave no consideration to the potential risks of long-term radiation damage as I wasn't expected to live long enough for it to matter.

The exception of epilepsy and the not insignificant psychological challenge of life with a life-threatening condition, the tumour didn't impact capacity to work and live a full life. Since then I have had two children, started my own business and travelled extensively with my family.

It was not until my tumour progressed in early 2014 that I realised the extent of a gradual visual and cognitive decline. The tumour had spread into my corpus callosum, and there is now radiation necrosis contributing to the damage. A second biopsy also showed that my tumour was an oligodendroglioma, not an astrocytoma. I had a partial resection of the tumour in August last year followed by six months of chemo.

A neuropsychological assessment conducted soon after the surgery confirmed that I have marked deficits in some areas, mainly visual memory, spatial awareness and orientation. Subsequent vision tests showed that I had also lost a section of my left peripheral field of vision. My surgeon told me that the damage was permanent and couldn't recommend any treatment.

After I'd recovered from the surgery, I decided to find out as much as I could about brain health and rehabilitation. I knew that many people recover some physical and cognitive functionality after strokes and other traumatic brain injuries



*Nicola Sheehan achieved a major goal when she comfortably ran a half marathon. Here she is photographed with her stepson Will after the run.*

and I wanted to find out if I could do the same. The first thing I found with the help of the NSW Stroke Association. It was a simple online-eye scanning program funded by the Stroke Association in the UK (<https://www.eyesearch.ucl.ac.uk/>) within two weeks of starting that therapy. I had stopped walking into furniture (and people!) on my left because my eyes had been trained to scan automatically into my 'blind spot'. I was off to a good start.

The next program I found was a brain training program that based on the new science brain plasticity. If you haven't heard the term then google it – it offers a lot of hope for those of us trying to reverse or arrest damage caused by a brain tumour and its treatments. The program I started using in January (<http://www.brainhq.com>) and with regular training over the past eight months my visual memory, long and short term memory, orientation and brain speed have dramatically improved.

I have found that my spatial and depth perception issues also noticeably improve the more I challenge myself. When I'm at home, I try to use my left hand

as much as possible, and I have started learning how to juggle and write with my left hand. The final thing I started doing was running. The exercise was a joint recommendation for brain health in most of what I have read - Anything that makes our heart pump is good for our brains. So after I finished chemo in March, I started running and training to compete in a half-marathon in July. Unfortunately (and unusually) exercise can be a trigger for my focal seizures so most of my training done on a treadmill in the safety of our garage. The training paid off, and I achieved that goal and ran a half marathon in Melbourne in July with the Cure Brain Cancer Foundation Team and raised close to \$5,000.

On the back of our team singlets were the words “Brain Cancer didn't bring me to my knees, it brought me to my feet.” What great words by which to live.

**Thanks, Nicola Sheehan for sharing your story. Send your patient or carer's story to [btaa@shout.org.au](mailto:btaa@shout.org.au)**

## Sharon's secondary BT journey

By Sharon Dei Rocini

**BTAA asked Sharon to tell us a little about her journey with the new immunotherapy drugs for secondary melanoma. Thanks Sharon.**

In May 2013 started having headaches difficult reading and things just didn't make sense anymore! I thought I was having a breakdown as I was very stressed at work and I had just lost my father.

ACT scan of the brain showed three tumours in the brain were what causing me the problem. These turned out to be metastatic melanoma. Secondary cancer from a skin cancer 'melanoma' that I had 5 1/2 years earlier.

I went in and had neurosurgery in Sydney, which removed two of the three tumours. The other tumour was in the brainstem and even my neurosurgeon couldn't get to it.

One week after the craniotomy I went in and had stereotactic radiosurgery done on the tumour. It slowed down the tumour for a few months.

The six-week scan in September 2013 after surgery showed a new tumour. So I was on to Sydney again to see the surgeon and had it removed.

The scan in January 2014 showed the one in brainstem growing again. The radiosurgery had moved it a little bit and the decision made that it could come out. The neurosurgeon removed it without any side effects.

The scan in April 2014 showed another new one. I now have scans every six weeks. The neurosurgeon removed my new tumour.

The July 2014 scan showed another two tumours had started growing so by now I knew they also had to come out. So in Aug 2014 my neurosurgeon did a double craniotomy.

So far I have had five brain surgeries with six craniotomies to remove 8 secondary brain tumours and these all happened in 14 months.

In October 2014, I started on the new immunotherapy 'Yervoy' which was a three-month course. In March 2015, I started on a new immunotherapy 'Keytruda'. Keytruda is the treatment I will be on for two years which has so far stopped new brain tumour recurrences.

I have now had 12 months free from brain surgery.

In between the brain surgeries I have had three lung surgeries also to remove many melanoma tumours. And I am about to have abdomen surgery to remove a tumour that hasn't responded to immunotherapy.

I feel the immunotherapy has kept the brain tumours away and I'm hoping it continues.



*Sharon Dei Rocini, a member of the ACT Brain Tumour Support Network*

## IMMUNO-ONCOLOGY

Thanks, Sharon. Good to hear of the progress of the first wave of the new immuno-oncology therapies.

The landscape for melanoma patients is changing quickly and positively.

The new immunotherapy drugs are promising to be game changes in the treatment of cancer.

We are expecting significant progress in brain tumour therapies in coming years.

It takes time.

Yervoy listed on the PBS for melanoma in 2013.

Keytruda (pembrolizumab), has now been included on the PBAC for melanoma in 2015. See [www.abc.net.au/news/2015-06-28/melanoma-drug-listed-on-pbs-saving-patients-thousands/6578554](http://www.abc.net.au/news/2015-06-28/melanoma-drug-listed-on-pbs-saving-patients-thousands/6578554)

Those attending the BTAA and CCQ Summit in Brisbane on **22 October** will hear an update on all the therapies from **Associate Professor Martin van den Bent** from the Netherlands and Michelle Stewart from the Cure Brain Cancer Foundation.

**Register for the forum at [www.btaa.org.au/events](http://www.btaa.org.au/events)**

See also BTAA's Clinical trials page on our web site [www.btaa.org.au](http://www.btaa.org.au)

### CLINICAL TRIALS WEBSITES

- Australian Cancer Trials website - Cancer Australia
- Australian New Zealand Clinical Trials Registry
- ClinicalTrials.gov
- Cancer Trials Australia
- Trans-Tasman Radiation Oncology Group

# THANKS FROM THE BTAA

BTAA thanks its donors. We are a volunteer-only organisation that receives no funding or concessions from any governments, besides from indirectly as donations to us are tax-deductible. Your funds continue to help grow the organisation and each day it is more capable, committed and able to assist to patients and caregivers.

Particular thanks to significant donations from:

**Deborah Whittaker**

**Julia Robertson**

**Nicola Sheehan**

**Robyn Scott**

In memory of the late **Nicola Scott**

In memory of the late **Sharon Le Roy**.

Thanks to those that held awareness and fundraising events including:

**Barry Walls** and friends Trivia Fund Raiser - Beanies for Brains

**Mel and Peter Johnson**, Mel Goes Grey in May 2015 – second fundraiser for BTAA.

**Mel Tempest**, Ballarat Body and Soul Health Fitness Studio.

**Susan and Mark Dalliston**, for awareness and funds, raised at Mark's 50th birthday – Ribbons and Cranes.

**Marcus Paul** and **Marcella Zemanek** and **Amanda Fintan** for support of the Ribbons and Cranes event.

Thanks also to **Bathurst Regional Council** representatives **Ian and Lisa North** who accompanied Bathurst Living Legend **Mel and her husband Peter Johnson** to Canberra to attend Ribbons and Cranes. Also thanks to **Bathurst Panthers Club** for support

## Support is available

To talk with experienced caregivers, call BTAA on the Freecall 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 Council Support

Cancer Connect telephone (13 11 20)

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

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

## Useful links

See a range of useful links  
<https://www.btaa.org.au/page/29/useful-links>

**Cynthia Chappell** and the patrons of Our Creations Little Shop of Shops, Wynyard for funds and handcrafted gifts for our paediatric packs.

**Andrea Conole** for handcrafted gifts in grey.

**Jordan Cowen** and **Honeywood School, Tasmania** – our youth ambassador.

Thanks also to those who used the Everyday Hero fundraising option including those who ran **The Sunday Mail Suncorp Bridge to Bridge** in Queensland for BTAA. **Sharon Gatehouse** (Number one fundraiser), **Danielle Payouw**, **Innocent Maramba** and **Mark Cooper** in particular.

Thanks also to **Andrew Simpson**, **Debbie Pollard** and **Sylvia Gallagher**, who make regular donations to BTAA.

Thanks to **John Malkovich** and **SOS Recruitment**.

Thanks also to the **John James Foundation**, Canberra, for a second major donation to support our Paediatric Project. BTAA provides a paediatric pack for families with children diagnosed with brain tumours. In addition to information materials we provide a small gift for the affected child and any siblings.

Thanks to the **Southern Cross Club**, Woden for assistance with the operations of the **ACT Brain Tumour Support Network**.

And to **GlaxoSmithKline** for further assistance with an educational grant to improve our website functionality to ensure information resources are readily available.



*Barry Walls Beanies for Brains Trivia fund raiser organiser wearing Andrea Conole creations*



*Mel Johnson receives her BTAA Ambassador certificate from Catherine and Di at Ribbons and Cranes.*



# 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!



Brain Tumour  
Alliance Australia



@BrainTumourAA



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



This newsletter was produced with the assistance of funds from Mel Goes Grey in May.

Editor **Susan Pitt** and **Mark Dalliston**

Designed by **Jon Shirley Creative**

Printed by **Mavericks Printers**

Authorised by **Susan Pitt**, 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.