BRAIN TUMOUR
ALLIANCE AUSTRALIA

BRAIN CANCER ACTION WEEK EDITION

27 APRIL TO 3 MAY 2014

This newsletter was produced with the assistance of Roche Products Pty Ltd

Sarah Mamalai and Renee Hindson with their take on a Hat for a Day for BTAA. Photo Susan Pitt.

INSIDE THIS ISSUE

LETTER FROM THE CHAIR

Hello all

In this issue to mark Brain Cancer Action Week from Sunday 27 April to Saturday 3 May we focus on how BTAA is building our alliances. We report on initiatives at the national and international level to strengthen and unite those calling for: better support for those living with brain tumours; more effective treatments, and more resources for the researchers working on the causes.

In October 2013 BTAA organised the first National summit of support group representatives who met to build our alliances in Sydney at a half day Summit following attendance at **COGNO**. Thanks to **Cure for Life** (now the Cure Brain Cancer Foundation) for providing financial support to enable people to gather in Sydney at the Cooperative Trials Group for Neuro-Oncology (COGNO) and to stay on for the BTAA Summit hosted by the Sydney Women's Club.

Congratulations to **Eng-Siew Koh** and her team for convening an excellent meeting in Sydney and making the consumer representatives welcome.

Representatives of support groups from across Australia shared their experiences and found a lot in common The issues facing groups operating in Adelaide, Perth, Canberra, the Gold Coast, Sydney, Melbourne and online were similar. Our agreed outcomes included:

- Continuing to advocate for brain tumour care coordinators;
- Using existing support group networks to assist other support initiatives;
- Developing a variety of support services delivered in person, online and via telephone;
- Rolling out the ACT Brain Tumour Network's 'Brain Bags' concept across Australia;
- Disseminating a 'health service, medical research and treatment update' specifically for conveners of local support groups;
- Asking convenors of existing face to face and online support groups what would assist them; and
- Holding another Summit in 2014 - to keep the spirits, knowledge and energy up in what is sometimes a tough unpaid role for volunteer BT consumer group convenors.

Informed by the BTAA Summit I headed to two international forums in San Francisco. The first was an International Summit convened by the International Brain Tumour Alliance (IBTA) which is covered in this issue by IBTA Chair **Denis Strangman**. The second was the Society for Neuro-Oncology (SNO) Annual Scientific Meeting. A summary of the SNO proceedings is available here http://www.theibta.org/SNO2013Highlights.pdf.

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LETTER FROM THE CHAIR, CONTINUED FROM PAGE 1...

Also at SNO was **Di Legge** who presented two posters at SNO. See her report below.

Also below read the stories of three health consumers on what motivates them. At BTAA's request **Jennifer Ley** writes about her son **William Ley**, **Rigoula Roussakis** tells her story and Susan Pitt reports on **Sarah Mamalai's** two Brainstorm events.

The New Year found me working (after my day job) on BTAA's submission to the Federal Government Budget 2014-15 processes. Our key recommendation remains funding to support increased access to specially trained, registered brain tumour care-coordinators to act as patient advocates, coordinating care for people with brain tumours, their families and carers. In addition we propose that the Commonwealth Government revisit the National Health Priority Area Cancers set some years ago, to ensure cancer control priorities are commensurate with contemporary needs. We also presented the Government several funding opportunities. A copy of our submission is available on our home page at www.btaa.org.au .

BTAA is a very small organisation in terms of operating costs, running on volunteers. During 2013 we received increased support for our activities through a variety of fundraisers. See our Thanks report in this issue. I make a special thanks to **Jesse Caridi** and his friend **Rowan Webb** who raised funds by growing long beards, then shaved them. Also my thanks to **Toni Badenach**, her family and her friends who held several fund raisers – walks and auctions – in Melbourne and Hobart. Michael Rosier writes about his golf challenge. And finally thanks to all those who supported our Wear a Hat for a Day for BTAA or just donated to our cause. Thanks to our supporters, including the family of **Nicola Scott**, we are now in a position to offer a number of education grants to **brain tumour care coordinators**. We will soon announce how we will assist the experienced brain care coordinators to attend international conferences and share their knowledge like **Di Legge** did (see her report on SNO in this edition). We would also like to encourage new brain tumour care coordinators to get along to COGNO, to be held in Melbourne in October 2014. **(See the diary dates at the end.)** Contact enquiries@btaa.org.au if you would like to contribute to this project working with BTAA's **Catherine Hindson** and **Jennifer Ley** – both registered nurses.

Another new initiative in 2014 will be around paediatric brain tumours. Thanks to funds raised from Peter Vanzwan and the Vanzwan Golf Day Fundraiser for BTAA, we are importing a new resource from Canada and will work on how to get resources into the hands of parents and health professionals in this challenging area. Contact enquiries@btaa.org.au if you would like to be involved in this project headed by BTAA's MaryAnne Rosier.

We continue to build our alliances with fellow travellers in other health consumer organisation like the **Consumers Health Forum** (see Our Voices story below), **Rare Cancers, Rare Diseases, Cancer Voices Australia** and many other groups to give a voice to those living with brain tumours and the health professionals who work on treating those with brain tumours or researching the causes or new treatments.

In closing I offer belated greetings for the year ahead 2014. As you will see from the diary dates it will be an exciting one.

Matt

Matt Pitt. BBiotech(Hons), MPH.
Chair, BTAA

BTAA Committee. L - R Denis Strangman, Mark Dalliston, MaryAnne Rosier (Basil the dog – Hat Day mascot and honorary member), Susan Pitt (Secretary), Jennifer Ley, Catherine Hindson (Treasurer), Kelly Webster (Vice Chair). Absent - Matt Pitt, overseas (Chair). (Photo Michael Rosier)

DURING 2013 BTAA

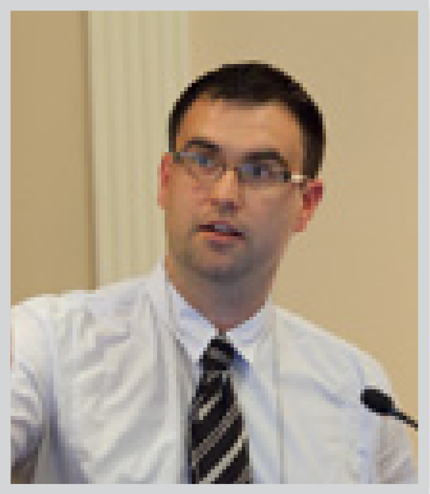
Distributed around 300 information packs to assist people new to the brain tumour journey.

Grew our data base of supporters to over 1,500. We send this newsletter to all our supporters free of charge twice in 2013.

Doubled our Facebook followers to 1,000.

Staffed a telephone contact **(Freecall from land lines 1800 857 221)** where newly diagnosed persons can contact **MaryAnne** - someone who has experience with the brain tumour journey. **MaryAnne** or her back up **Denis Strangman** and **Susan Pitt** from the committee talk to several newly diagnosed persons or their family members each week, to listen and refer them to available support services: their nearest face to face support service; or online services including **the Cancer Council's Cancer Connect.**

INTERNATIONAL NEWS



BTAA Chair Matt Pitt speaks on the first day of the IBTA Global Summit (Photo Paolo Salcido)

International Summit

In recent months the big news on the International Brain Tumour Alliance (IBTA) front has been the holding of the First World Summit of Brain Tumour Patient Advocates in San Francisco in November 2013, which was attended by 64 advocates from 20 countries, including BTAA's Chair Matt Pitt.

The Summit was addressed by specialist neuro-oncologists Dr Susan Chang from the University of California, San Francisco, (who spoke at the BTAA Forum in Brisbane held in August 2012) and Texan Dr Virginia Stark-Vance, who is credited with the discovery of the relevance of Avastin for brain tumours.

While there were participants from Asia, Africa, the Americas and Europe, participants from the Asia-Pacific area were short on the ground. This raises the question – could we in Australia be doing more to help those who have a brain tumour and reside in our geographical area?

This includes Papua New Guinea and Indonesia. I know of an Australian neurosurgeon who visits PNG to undertake pro bono work during his holidays but, as far as is known, cancer therapy services (chemo and radiation therapy) in PNG are very limited.

Nor are things much better in Indonesia, although there is a smattering of specialised cancer services.

Those who have the money probably go to Singapore for services unavailable in their own country.

Note that we do not refer to people who are "diagnosed" with a brain tumour in the less developed countries because many probably never receive a proper diagnosis and might even die without knowing that a brain tumour was the cause.

In front of the IBTA display at SNO. Left Denis Strangman, third from left Kathy Oliver (IBTA Co-Director, UK), third from right Di Legge (Brain Tumour Support Officer, The Austin).

SNO

Following the Summit a number of participants also attended the Annual Scientific Meeting of the Society for Neuro-Oncology (SNO).

SNO is the "de facto" international professional body for oncologists and other specialists, such as neurosurgeons and neurologists, who focus on brain tumours. At SNO I spoke with Dr Lawrence Cher (Vic), Professor Mark Rosenthal (Vic), and Dr Helen Wheeler (NSW). According to the program there were some other Australian specialists present. Di Legge from The Austin (Vic) was also there (see photo of Di with several of the advisors who helped organise the IBTA Summit).

International Awareness Week

The IBTA is currently in the process of inviting brain tumour and cancer-related groups to support its two major awareness-raising projects of the Walk Around the World for Brain Tumours (1 January – 31 December 2014) and the International Brain Tumour Awareness Week (26 October – 1 November 2014). See the IBTA website for further information: www.theibta.org

Last year 167 organisations were happy to be listed. These IBTA projects have been taking place for eight years. In some countries they already have a week, a day, or even a month, dedicated to brain tumour awareness-raising but that does not stop them from also joining with the IBTA for the International Brain Tumour Awareness Week which is held traditionally in late October – early November. The Canadians, for example, have long selected October as their brain tumour awareness month and organise a series of what they call "Spring Sprints" around the country.

Brain Tumour magazine

Each year the IBTA produces a magazine of over 100 pages, containing stories about brain tumour patients, caregivers, specialists and others. The 2014 issue is being assembled now. Twelve thousand copies are printed and distributed for free in 109 countries. All BTAA contacts for whom we have a valid postal address will receive their copy posted direct from the UK by the IBTA's bulk mailing agency.

Note - All people who receive the BTAA Newsletter by post and whose email address BTAA is aware of also receive the monthly E News from the International Brain Tumour Alliance (IBTA). This occurs because of a historical connection between the two organisations. Consequently, readers may have seen short references to some items mentioned above in the IBTA E News. If you wish to subscribe to the free monthly IBTA E News visit the IBTA website and click on the on-line subscription link.

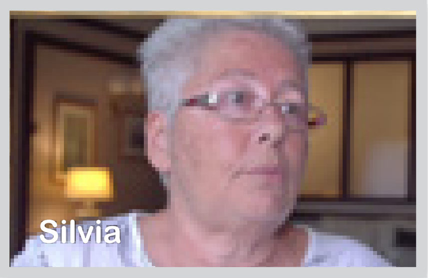
Denis Strangman
Committee member,
BTAA Chair, IBTA.

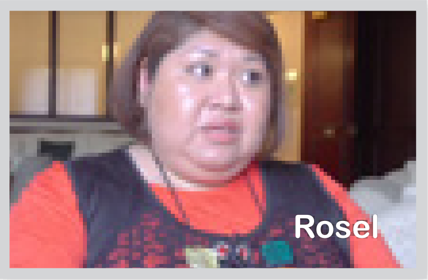
SPREAD THE WORD!

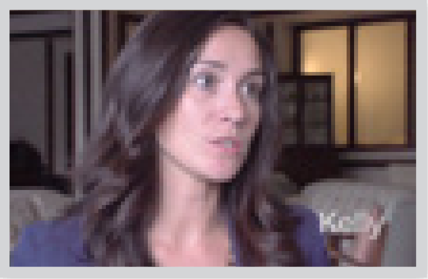
Please LIKE, ADD, SHARE, COMMENT and SPREAD the word via our Twitter, Facebook and LinkedIn accounts! This not only helps our voice to be heard but also gives you a chance to reach out, interact and communicate with BTAA and the wider brain tumour community!

Brain Tumour Alliance Australia

@BrainTumourAA







OUR HEALTH OUR STORIES

By Susan Pitt, Secretary, BTAA

What consumers – patients, their carers and their families – think about healthcare matters. The views and experiences of consumers can tell a lot about what works and what doesn't, and how healthcare could be improved.

Brain Tumour Alliance Australia Inc (BTAA) is working with the Consumers Health Forum of Australia (CHF) to discover and share the stories of healthcare consumers.

During November we engaged **Daniel Sanguineti** and his team (**Michael Watson** and friends) to film and edit six stories to upload on the CHF web site. The first story was Sarah Mamalai's. She said ***"How can it be such a terrible statistic, and kill so many people - from babies to old men - and no one knows?"***

See http://ourhealth.org.au/stories/raising-awareness-sarahs-story

I had the privilege of interviewing Sarah and nine other fantastic advocates off camera while Daniel filmed. **Steve, Yvonne, Jarrett and Nalani Anthoney's story, John Croft's story, Silvia Zagel's story, Kelly Webster's story and Andy and Rosel Stokes video stories** should be up by the time you read this newsletter. Look for a link on the BTAA home page and the CHF Our Stories site. Thanks also to Renee Hindson and **Mark Dalliston** who have both shared their stories on the OurVoices site as well as contributing their story to the Rare Cancers organisation.

We would you to contribute to the discussion we have started on the OurHealth website.

If you have any questions about this discussion, or about OurHealth, please contact Susan Pitt, Secretary, secretary@btaa.org.au or CHF directly on 1300 700 214.

See this page – two issues: care coordinators and awareness of the impact of BTs.

http://ourhealth.org.au/tags/brain-tumour

Consumers can start more conversations.

Stop press – The two videos are now on ***OurHealth*** at *http://ourhealth.org.au/stories/making-a-difference-btaa-members-share-their-stories* & *http://ourhealth.org.au/stories/daineres-journey-anthoney-familys-story*

The CHF is the peak national body representing the interests of Australian health consumers, and with funding from the Commonwealth Department of Health, they have developed the OurHealth website – www.ourhealth.org.au. OurHealth is a place where patients, carers and families can share their healthcare experiences and their ideas about how to improve healthcare in Australia. This helps consumer advocates and consumer organisations to identify and work for changes that will improve things for patients, carers, families and communities.

Thanks to Sanguineti Media http://www.sanguinetimedia.com.au/#!brainstorm/c24dt

MEMBER STORIES

GOLDEN OPPORTUNITIES AT SNO 2013

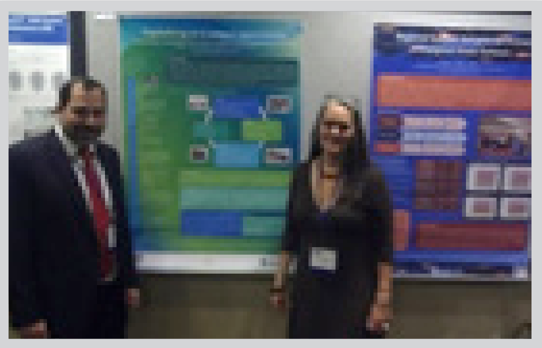
By Di Legge, Brain Tumour Support Officer, Olivia Newton-John Cancer & Wellness Centre, Austin Health, Melbourne

When Consultant Neuro-Oncologist, Lawrence Cher suggested earlier last year that we should submit an abstract for the upcoming Society for Neuro-Oncology (SNO) Annual Scientific Meeting in San Francisco, I found it difficult to envisage that it would actually bear fruit. Happily in August we received the news that our 2 abstracts titled "Capitalizing on a unique opportunity: the Brain Tumour Support Officer role at Austin Health" and "Regional support network for primary malignant brain tumours" were accepted for poster presentation. We were excited and grasped the opportunity to showcase the brain tumour support work at the Austin and beyond.

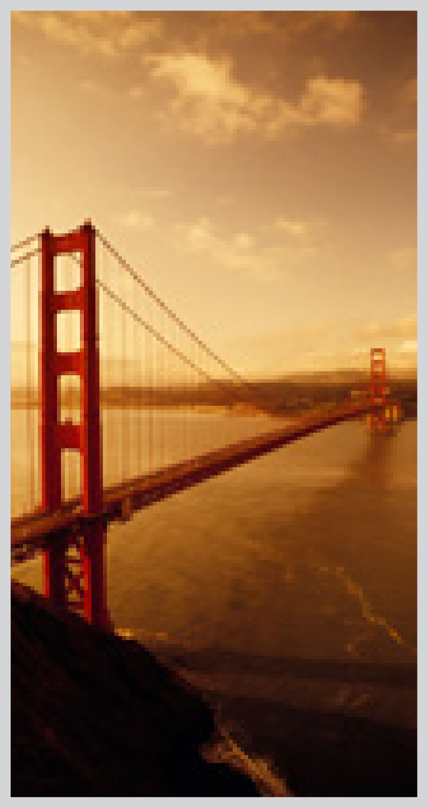
In 2013 the SNO meeting joined together with the World Federation of Neuro-Oncology, so drew health professionals and clinicians from around the globe to discuss issues in diagnosis, treatment, research and support for people with brain tumours. Close to 2000 delegates attended and hundreds of posters were displayed representing work from all over the world. It was a truly amazing experience. I had the opportunity to meet with other care coordinators and discuss similarities and differences in our roles and services. We also shared ideas about enhancing services for people we work with, research opportunities and how to get support for both ourselves in this role.

Conferences such as this highlight the important work that is happening across this field in clinical trials and new treatment. The Quality of Life Education Day gave a focus to areas such as fatigue management, new technologies for cognitive retraining and supportive care. There were a number of ideas and strategies I am keen to incorporate into our practice, especially in the area of survivorship. However, it was encouraging to realise that services provided in Australia are at a world class standard & incorporate best practice principles. I found that delegates were interested in what we were doing in Australia, and how we have pulled together supportive care programs with grants and philanthropy, and the ways in which we are resourcing patients & families affected by brain tumour.

So now I have returned to Australia with a renewed enthusiasm for our program, some ideas for change and a bit more knowledge about challenges faced and how best to support patients facing these challenges. Thanks to BTAA for providing some financial assistance to make the trip to San Francisco possible, it was a valuable opportunity to connect with, and learn from others in brain tumour treatment & support.



Poster viewing session at SNO with Lawrence Cher and Di Legge.

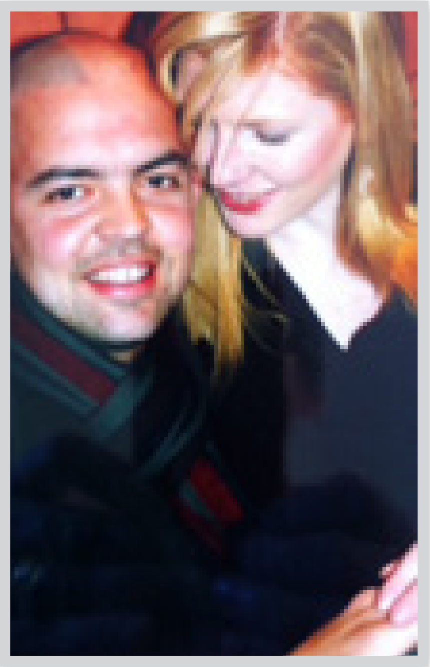


Golden Gate Bridge San Francisco

The Brain Tumour Support Service based at Austin Health provides a range of services to people affected by the diagnosis of a primary brain tumour including a monthly support group, information/ education programs, individual support appointments and support for carers'. The Brain Tumour Support Group is held on the 2nd Wednesday of the month 11am-1pm at the Olivia Newton-John Cancer & Wellness Centre, 145 Studley Road, Heidelberg. Contact person is Di Legge (Brain Tumour Support Officer) 9496 3315 or btso@austin.org.au

The support group is open to anyone affected by the diagnosis of primary brain tumour: patient, carer, family, friend & does not need to be an Austin Health patient, they can attend, as long as they can get there.

William Ley



Will and Fiona

WILL'S STORY

by BTAA Committee member Jennifer Ley, Sydney

A chance CAT scan ordered by his local GP following a game of AFL football, led to the diagnosis of my son William's brain tumour. Will was 27 yrs old when he was diagnosed with an oligoastrocytoma Grade 3 in the left frontal lobe. He was a university graduate, busy working and playing sport and feeling fit and well when his life and the lives of his girlfriend, Fiona (later his wife), his parents David and myself, two younger sisters Natasha and Stephanie and younger brother Timothy were changed forever. Will recovered quickly after operations, radiotherapy and oral chemotherapy.

Personally, I felt a strong urge to wrap Will up in cotton wool, but Will was never going to be ruled by the constraints of a brain tumour. He was fortunate to have a father (and a more cautious mother), siblings, mates and especially a wife who shared, helped and encouraged Will to pursue his dreams.

To many it seemed that Wills tumour was non- existent as for a long period he contradicted the fateful predictions of his doctors and experienced reasonably good health. Will managed to work to his capacity, drive a car and coach junior football for a few years. He coped bravely with fluctuating periods of short term memory loss, tiredness, speech and balance issues. Will often said that his diagnosis was worse for those around him than it was for himself and that he didn't feel sick! Those close to him tried to get on with their lives but lived with the constant threat to Wills health. Will and his wife had a beautiful wedding and together enjoyed life and travelled on adventurous trips including sailing around the Greek Islands and Dalmatian coast and skiing in Japan and South America.

Will loved life and people and had much to live for, but sadly after more than five years, he had tumour recurrence before he holidayed with his family at Christmas, flew to Ayers Rock with Fiona to watch the sunrise on New Year's Day and bravely faced a few months of decline. Will died peacefully in March, 2011, aged 32 years.

Wills family and friends walked at Centennial Park last year for Cure 4 Life. We spoke to Dr Charlie Teo and I told Dr Teo that I'd like to help other people who have brain tumours. He suggested that I contact Matt Pitt, BTAA chairman. BTAA assists people with brain tumours throughout their life from the time of diagnosis and gives support to their families and careers. Shortly afterwards I met BTAA committee members, Catherine Hindson and Mary Anne Rosier who travelled from Canberra and Kelly Webster from Sydney. We discussed how I might join Kelly as Sydney based committee members and work on projects such as a Brain Tumour support group at RPA Hospital.

I did learn a lot about brain tumours after Wills diagnosis, I researched and attended conferences with my husband, trying to educate myself about brain tumours, the latest research and treatments in an attempt to help Will to be one of the lucky ones who beat their disease. I have now joined the committee of BTAA and hope my experiences and knowledge will benefit others.

NEW COMMITTEE MEMBER

BTAA welcomes Will's mother Jennifer Ley to our committee. Jenny is a Registered Nurse and Midwife. Jennifer currently works as a certified school vaccination nurse for the NSW Depart of Public Health. Will's father David has offered to help BTAA prepare a new business plan.

RIGOULA'S STORY

By Rigoula Roussakis of Melbourne.

My life was what people would call 'a normal life' pre my diagnosis.

I was a career woman wanting to succeed and do the best I could in my job as an Executive Officer – Drug Policy for a local government authority. I was married had a great family and friends and a happy fulfilled life. My name is Rigoula (I am known as Rigs) and I am now 44 years old.

In March 2002, when I was 33 years old, the best thing that occurred to me was the birth of my daughter. Life was fantastic and I was trying to be the best mother that I could be for her.

In August 2002 all that changed. I had a seizure overnight in bed. People always ask me did I ever have headaches or any other symptoms before this. My answer is always 'no, never'. At the time I put the seizure down to sleepless nights waking every four hours to breastfeed my daughter.

The next day I went to see my GP who advised me to have a CT scan. A couple of days later I was called back and was told that I had a brain tumour which was the size of a lemon and needed urgent surgery. I was operated on within 5 days and most of the tumour was removed but not all because it was entwined with my brain. The biopsy revealed it was a Grade 2 mixed oligoastrocytoma tumour part of which I still have and is monitored by an MRI every few months. I have had over 25 MRIs in the past 11 years.

At the time of my diagnosis I had a very strong determination that I would survive this. I was told that I may not. All I wanted to do when I heard the diagnosis was to see all the people that I had known throughout my life. I was positive but they were all devastated. I recall trying to calm them down and I must say I never shed a tear. I now look back and view this as an amazing strength that I have to be more concerned for others than myself.

My seizures continued after my operation having up to 5 a day in the first few years. I was either sleeping all day or going and seeing numerous neurologists and oncologists to try and discover the right combination of medication. Fortunately they have now been controlled and I would like to thank Professor Mark Cook from Melbourne's St Vincent's Hospital, my epileptologist, for this outcome.

Life changed for me in 2002 – My daughter was born in March, I was diagnosed with my brain tumour 5 months later in August and in October I separated from my husband.

In August 2012 I was also diagnosed with having an ovarian tumour. Another road to survival. I was operated on within a week to remove it. Unfortunately a few days later the biopsy showed that it was a very rare type of cancer called Sertoli-Leydig cell tumour only found in approximately 0.5% of all Ovarian tumours. I had to have a further operation to remove all my reproductive organs. I always say that 'I am the lucky one'. I am now undergoing regular MRI's for this also.

In August 2013 I was diagnosed with having a suspicious growth in my breast called Hyperplasia. I had another operation and it was removed. It was diagnosed as a growth which was preparatory to developing into cancer. Because of my previous health issues and a history of breast cancer in my family I chose to have an MRI instead of a mammogram and the growth was revealed. Lucky once again!

During my journey over the past 11 years I tried as many ways as possible to survive. These included meditation, yoga, natural remedies and a healthy diet cutting out all sweet food and no chocolate and no tea or coffee to this day.

My priorities in life have changed with all the medical experiences I have gone through.

For myself, my goal is survival to see my daughter grow up by maintaining my health and strength for as many, many years as I can.

Rigoula Roussakis

Rigoula Roussakis is a Melbourne based health consumer representative on:

- **Medicines Australia Code of Conduct, Monitoring Committee consumer representative**
- **National Prescribing Service (NPS) Consumer Advisory Group**

She previously served on the Medicare Local Bayside – Quality of Medicines (QUM) advisory group.

Rigoula is a member of the Epilepsy Foundation of Victoria and BTAA.

Reflecting on my previous life before 2002 my most negative action was that of 'worry worry' in all respects of my life. Now I say that the most important matter is to not worry but to focus on positivity and strength of mind to ensure continued health, happiness and love to all.

SARAH'S BRAINSTORMING STORY

By Susan Pitt, Co-convenor of the ACT BT support network

Sarah Mamalai Brainstorming Parliament House Image Susan Pitt

Sarah Mamalai was diagnosed with a brain tumour during 2007 as a mother of two very young sons. I met Sarah during 2009 when she attended some of the ACT brain tumour support network meetings. There she met her young 'soul sista', the late Canberra author Dainere Anthoney – with whom she shared a birthday. www.dainere.com – and other fellow travellers

Sarah is a barn stormer. She is unstoppable. Since diagnosis she has been through treatment, raised walked Kokoda, motivated her many friends to run as the 'Mamalai Mummas' and more. All the time she has had the support of her husband Oscar and her two boys Will and Joe.

In 2011, motivated by the grief of losing too many friends to the disease, Sarah came up with the idea of raising funds through a big event. This evolved over time and trials into two big events: Brainstorming Parliament House in November 2013 and Brainstorm for a Cure – A 40th birthday party with a purpose in February 2014.

Sarah Brainstormed Parliament House in October 2013. Speakers included Associate Professor Charlie Teo, Renee Hindson, Yvonne Anthoney and Sarah.

Sarah had the vision and called on many people to make her vision of Brainstorming Parliament House a reality. The Canberra Weekly magazine provided great coverage of Sarah's events. Senator Zed Seselja attended and the Parliamentary Brain Tumour Awareness Group Co-convenors Senator Catryna Bilyk and Scott Ryan sent a message of support.

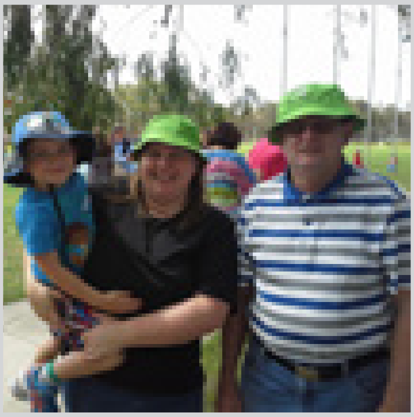
Sarah was assisted by coordinator Dianne Smyth, many friends including Amanda Fintan, Justine Nagel and others including the ACT BT Support Network. She even had Michelle Murray up late the night before at Sarah's organising the visual display.

In February 2014 Sarah hosted Brainstorm for Hope – A Party with a Purpose – to mark the milestone of her 40th birthday. Sarah and over 550 guests partied at the Australian Institute of Sport in Canberra to raise awareness and funds for Cure4Life (now the Cure Brain Cancer Foundation), BTAA and Ronald McDonald House.

Amanda Fintan and Daniel Sanguineti combined to get singer/dancer Timomatic. Timomatic came to fulfil Dainere's wish what was to have been her 16th birthday. Dainere's sister Nalani delivered her message to Sarah. A great job done by MC Andy Trieu, comedy from Greg Fleet, dancing to the sounds of Tuchasoul, and entertainer Michael Stangel. The event was streamed live.

Sarah made a great speech acknowledging the terrible burden her disease had been on her family and friends. Amongst the many she thanked she noted John Newman and Phil Dunne who rode from Sydney to Canberra for Sarah's Brainstorm's party.

https://twitter.com/Brainstorm4cure?original_



Zac, Emma and Andrew

THANKS FROM THE BTAA

Jesse and Rowan (pictured right) raised more than $7300 for the BTAA.

SHAVE FOR A CAUSE

Canberra Times, Matthew Raggatt, December 03, 2013

Before: Jesse Caridi, of Narrabundah, left, and Rowan Webb, of Kambah, have been growing their beards for several months to raise money for The Brain Tumour Alliance. Photo: Melissa Adams

Jesse Caridi is in the business of keeping people cool, and Tuesday's 33-degree heat is sure to pose no problems now the air-conditioning specialist's nine-month charity beard has been left on a pub floor.

Mr Caridi, 26, joined workmate Rowan Webb to bid farewell to their hairy black coverings at King O'Malley's Irish Pub on Monday, having raised more than $7300 for a brain tumour support body close to the Narrabundah man's heart.

"We won't be sad to let them go - winter was nice, they kept us warm, but it's getting too hot now," Mr Caridi said.

"Three years ago my stepfather had headaches, then he went to hospital and we found it was actually a brain tumour - it took us all by surprise."

Mr Caridi said Brain Tumour Alliance Australia provided information and a support network after his stepfather Chris Butel was diagnosed with an aggressive stage-four brain tumour.

The successful businessman has started to lose his speech, sight and hearing and can no longer read or write.

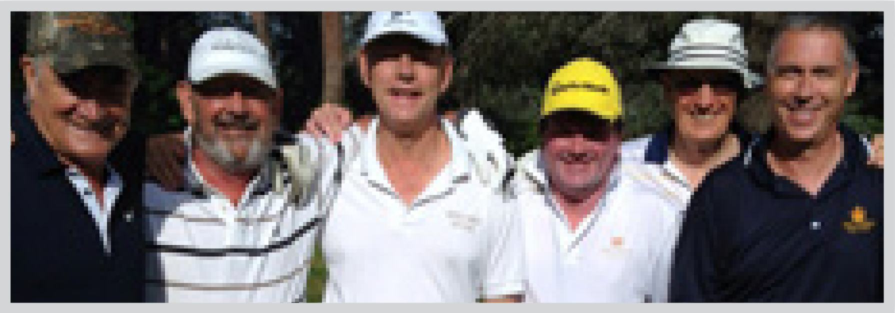
http://m.canberratimes.com.au/act-news/bearded-brothers-join-fight-against-hairy-enemy-20131202-2ymf3.html

HOW ABOUT A FEW ROUNDS OF GOLF FOR A GOOD CAUSE?

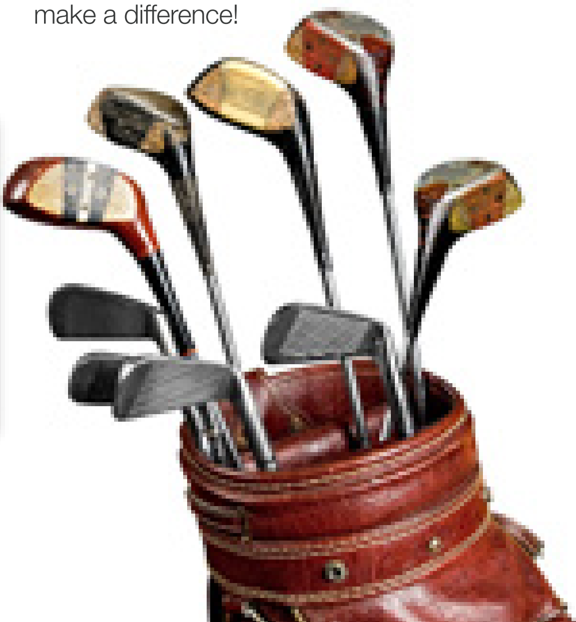
By Michael Rosier

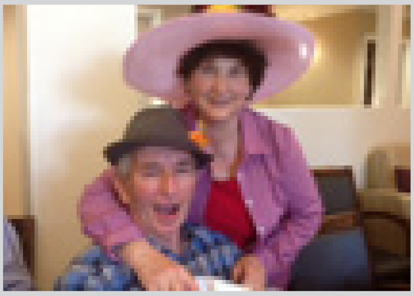
A group of Canberra golfers has donated funds to BTAA to help launch the distribution of the Paediatric Brain Tumour Handbook to paediatric medical and allied professionals and also the families of a child with a brain tumour.

The idea to raise money for this, and other needy causes, was the brainchild of golfer Tony Trobe who plays at The Royal Canberra Golf Club. Tony and his golfing mates play together regularly and previously would enjoy a ''side bet" or two during the round. They decided that, rather than exchange golf balls or small change, they would put money into a pot every week and then donate the accumulated funds. Over the last five years they have collectively raised thousands of dollars to donate to causes where they see the need for an injection of funds. BTAA's project obviously fits the description and hopeful can make a difference to the families involved. The golfers are now challenging other regular golfing groups to consider using the same approach and to help make a difference!



Some of the RCGC group, left to right, Ray, Don, Tony, Richard, Chris and Peter





WEAR A HAT FOR A DAY FOR BTAA

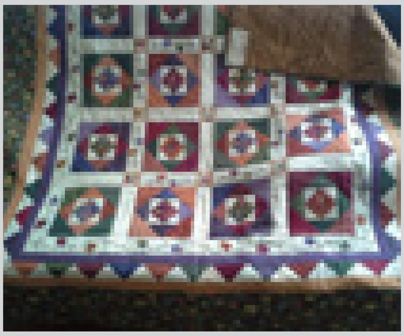
Thanks to MaryAnne Rosier for coordinating a great "Wear a Hat for a Day for BTAA". Thanks to all those that held a Wear a Hat for a Day for BTAA:

- Australia Post, including Walter Winkler, Julie Hunter and Chris Wilson and other staff at Australia Post in support of a colleague.
- Debbie Pollard and the team, Audit and Fraud Control Division, Department of Defence.
- Emma Warwick and the Gordon Early Childhood Centre and ACT Pathology at the Canberra Hospital.
- Jennifer Paton and friends, Goulburn.
- Barbara Gabogrecan Drouin VIC.
- Laura Rosier, Lyneham Primary School. ACT
- Lucy Badzim, in memory of Nives Leslie, and the Canberra Girls Grammar School. ACT.
- St Mary's Senior High School, St Marys NSW.
- Blaxland High School, Blaxland, NSW.
- St Gregorys Queanbeyan.
- St Columbans, Caboolture.
- Land Services Group.
- Sinead Strawbridge, Our Town Our Country. Alice Springs.
- Capital Women's Health.
- Cassandra Tragar.
- Vicki O'Beirne, Dennis O'Beirne, Carlie Cutfield and Tracey Seccombe who helped with Hat Days at Newcastle Private Hospital ,Blackbutt Doctors Surgery & Thorton Medical Centre.
- Andrew Donnelly, Chaplain, Kingsville Aged Care Facility, VIC.
- Michelle Cochran.
- Spotlight Hat Day, Queanbeyan. NSW.
- D & N Warren Hat Day.
- Chris Wilson Hat Day.
- Louise Young and Booragoon BTAA Hat Day
- Peter Scott and ORS Group.
- QLD Hearing Loss Family Support Services.
- Lorraine Purcell and friends, Wandal.

Mark, Cara and Susan Dalliston with MaryAnne Rosier. Cara presented the Hat Day cheque at the Canberra Girls Grammar Junior School Hat Day

THANKS ALSO FOR ASSISTANCE TO…

- Cure Brain Cancer Foundation (formerly Cure for Life) for support for BTAA Support Network meeting October 2013 to offset travel and accommodation costs for the meeting.
- Consumers Health Forum for support for the Our Stories project
- Catherine Smith and Wholistic Financial Services for assistance with auditing.
- Colin McCulloch for services to BTAA and Brainstorm.
- Colin Burk, Swell Design Group, for design help for Sarah's Brainstorming Parliament House.
- Daniel Sanguineti , Michael Watson and Sanguineti Media for video services for BTAA and Sarah's Brainstorm.
- Marcia McGoogan for a beautiful bed topper for Brainstorm.



Thanks to Marcia McGoogan for the bed topper for Brainstorm.

THANKS FOR THE SIGNIFICANT DONATIONS FROM…

Roche Products Pty Ltd for support for this newsletter and educational events.

Jesse Caridi and Rowan Webb. Beard grow and ''shave off"

Peter Barclay OAM, King O'Malley's Irish Pub, Canberra.

Vanzwan Accounting Plus Annual Charity Golf Day, Canberra.

Brainstorming Sarah Mamalai and her team led by Amanda Fintan.

Gavin Jaeger and Jason, JAGAMA for Toni Badenach, Art event, Hobart.

Karen Oxenham and Justin Foster, Auction and Walk for Toni Badenach, Hobart.

Thanks for a Xmas donation June and Kevin Leroy in memory of Sharon Leroy. New Brighton,

Donations from family and friends in memory of Jenelle Irene Hodge, Inverell NSW.

National Capital Private Hospital "Surgical Ward staff".

Rotary Club of Newcastle Enterprise.

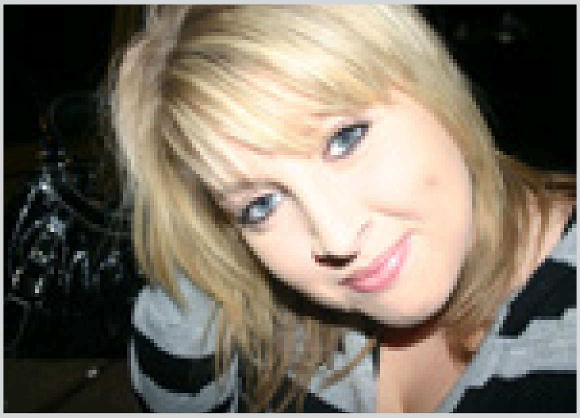
Rotary Club of the Lower Blue Mountains.

Donations from Ivor Lennon and family and friends in memory of Father Paison (Peter) Jaidee. ACT.

Donation from Michael and Tracy Scott, from Queensland, in memory of their daughter Nicola.

Thanks to Tim and Shaun @ Canberra Web for work on Nicola's tribute page.

And thanks to our regular donors Debbie Pollard and Andrew Simpson.



Nicola Scott. Who loved purple and butterflies.
www.btaa.org.au/nicola-scott.html

WALK FOR TONI

Thanks to all those who Walked for Toni (and BTAA)

My name is Toni and I have brain cancer but I have the most amazing family support to assist me through this arduous journey.

So little financial resources are directed towards brain cancer research and in making the community more aware of the issues surrounding brain cancer and the issues brain cancer patients suffer. As such my beautiful and generous sister, Kristy and her equally beautiful and generous friends Amanda, Ingrid and Dana arranged to participate in the Point to Pinnacle Walk/Run from Wrest Point Casino in Hobart to the top of Mount Wellington, which sits behind the city of Hobart on 17 November 2013 and seek donations for BTAA.

My cousin, Gavin and his partner, Jason own Jagama, a Hair & Lifestyle Store ("Jagama") in Sandy Bay in Hobart. In addition to owning and working in Jagama, Jason is an accomplished artist and on 30 November 2013 Gavin and Jason held a fundraising auction to raise, in part, money for BTAA.

I am so grateful to my family for not only supporting me emotionally through this incredibly difficult time but also in their fundraising activities. Words are simply not enough to thank them all.

SUPPORT BTAA

BTAA APPRECIATES YOUR SUPPORT

YOU CAN:

Use the Everyday Hero Channel

www.everydayhero.com.au/charity/view?charity=2051

Donate directly to BTAA.
CBA. BSB: 06 2900.
Account Number: 10603153.

Send a cheque made out to
BTAA to PO Box 76
Dickson, ACT, 2602.

BTAA has been endorsed by the Australian Taxation Office as a Deductible Gift Recipient

BECOME A FINANCIAL MEMBER OF BTAA

Please visit:
www.btaa.org.au/supportbtaa.html

Entrance fee: **$20.**

Annual subscription: **$10** payable up to five years in advance.

Or email **treasurer@btaa.org.au**

APPOINTMENTS

Congratulations to Dr Cath Holliday and Ms Alanah Bailey, who were appointed Chair and Deputy Chair of the NSW Oncology Group in December 2013. Thanks to outgoing Chair Dr Kerrie McDonald and Deputy Chair Dr Liz Hovey for their achievements.

Enquiries to NSWOG@cancerinstitute.org.au (02) 8374 5600.

USEFUL LINKS

BTAA www.btaa.org.au

IBTA www.theibta.org

BTAI www.btai.com.au

COGNO www.cogno.org.au

Virtual Trials www.virtualtrials.com

Links www.virtualtrials.com/btlinks

Survivor stories
www.virtualtrials.com/survive.cfm

The Brain Hospice
www.brainhospice.com/

E-News services

IBTA (www.theibta.org/IBTAENewsDec2013.htm) sent to all BTAA supporters.

The Musella Foundation
www.virtualtrials.com/news.cfm

The American Brain Tumour Association (www.abta.org/news/enews/

The USA based National Brain Tumor Society (http://blog.braintumor.org/enewsletter/

The Brain Tumour Foundation of Canada (www.braintumour.ca/2310/subscribe-today)

The UK 'umbrella' group the Brain Tumour Charity UK (http://www.thebraintumourcharity.org/news)

CONTACTS

AUSTRALIA

BTAA Freecall (from landlines) number 1800 857 221. Enquiries@btaa.org.au www.btaa.org.au

Cancer Council. Call Cancer Council Helpline on 13 11 20 (toll free) Monday to Friday, 8am to 8pm. Coordination of Cancer Connections, Felix Ratcliff, felixr@nswc.org.au

Australian Pituitary Foundation Ltd. Ph 1300 331 807. Email: support@pituitary.asn.au Website: www.pituitary.asn.au

Acoustic Neuroma Association Australia
www.anaa.org.au/contacts.htm

Brain Foundation
www.brainfoundation.org.au

STATE/TERRITORY SUPPORT SERVICES AND GROUPS

Visit http://www.btaa.org.au/support_groups.html

AUSTRALIAN CAPITAL TERRITORY

ACT Brain Tumour Network. Susan Pitt, btsupport@btaa.org.au or call Susan on 0404255156

Canberra Hospital. Dr Anna Burger. Psycholo-oncology Clinic. The Canberra Hospital 02 6244 2188." A care co-ordinator who covers brain tumour patients was appointed in October 2011.

Canberra Hospital Brain tumour care coordinator Kylie Tinbury. 61744416 or 0478 402 288 Email: kylie.tilbury@act.gov.au .

TASMANIA

Royal Hobart Hospital. Neuro-Surgical Unit. Caitlin Daniels. Caitlin.daniels@dhhs.tas. gov.au

VICTORIA

Austin Health. Contact person is Di Legge (Brain Tumour Support Officer) 9496 3315 or btso@austin.org.au

Cabrini Health Neuro Oncology Care Coordination. Contact Lauren Todorovic 0427 586 443 or ltodorovic@cabrini.com.au

Royal Melbourne Hospital. Contact Marcia Fleet 03.93424589 or marcia.fleet@mh.org.au.

Hume RICS
Wodonga, VIC. 02 6057 5206.

Melbourne. Grey Matters. Contact Janet - 0422 639 993. thegreymatters01@gmail.com See also www.braintumourahoyhoy.org.

Talking Heads
Blackwood 8. Sally White on sally@sallywhite.com.au or seewww.blackwood8.com.au.

BrainLink Services Ltd
(Melbourne) www.brainlink.org.au 130 Freecall: 1800 677 579 info@brainlink.org.au

WESTERN AUSTRALIA

Brain Tumour Association Western Australia. Contact Louise Young Phone: 08 63146680 braintumourwa@hotmail.com www.braintumourwa.com

Sir Charles Gardiner Hospital: Medical Oncology inquiries 93461222, Radiation oncology inquiries 93464900, MRI Inquiries 93467900.

WA Cancer and Palliative Care Network has a cancer care coordination service nurse coordinator. Contact Anne King 0400 021649 or 08 92220202 anne.king@health.wa.gov.au

James Crofts Hope Foundation, John Crofts, info@jamescroftshopefoundation.org.au Contact Viviana 0416 118 077, John 0428 247 319.

NEW SOUTH WALES

Liverpool Hospital. Wafa Trad, neuro oncology care coordinator. Contact: wafa.trad@sswahs.nsw.gov.au

Marina Kastelan is a brain tumour care coordinator at the Northern Cancer Institute. 02 8425 3610.

Gosford/Wyong Hospitals. Colleen Stevens Neuro Cancer Nurse Coordinator. 02 43202187

Prince of Wales Hospital, brain and spinal tumour support group, Contact Alanah Bailey (02) 93823802 or alanah.bailey@sesiahs.health.nsw.gov.au

Westmead. Neuro- Oncology Information Network. Emma Everingham 02 8837 8926 02 8837 9000, page number 9 everinghame@ramsayhealth.com.au

Newcastle. Hunter Brain Tumour Network. Contact Kaye Duffy kduffy@hunterlink.net.au or phone 0413 275 853.

SOUTH AUSTRALIA

Adult Brain Cancer Support Association. See Facebook. Contact: Andy Stokes. andy.stokes@sa.gov.au

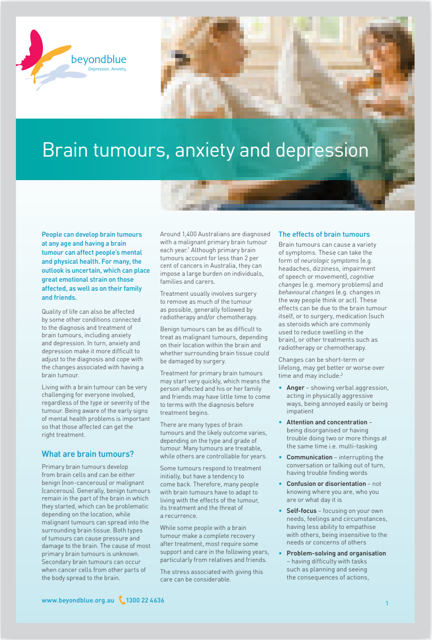
QUEENSLAND

Brain Tumour Support Service. Cancer Council Queensland.

Brain Tumour Support Nurse at the Princess Alexandra Hospital. Emilia Hunt, Ward 2C, Neurosurgery, Phone 07 3176 2137. btan_pah@health.qld.gov.au

The Neuro Foundation
(formerly BrizBrain and Spine). Vivien Biggs, Neuro-Oncology Nurse Practitioner. (07) 3833 2500. 0447448400

Gold Coast. Contact Pete McLaughlin 0422784885 or 0755983709. Email: petershark72@hotmail.com



beyondblue
Depression. Anxiety

Brain tumours, anxiety and depression

People can develop brain tumours at any age and having a brain tumour can affect people's mental and physical health. For many, the outlook is uncertain, which can place great emotional strain on those affected, as well as on their family and friends.

Quality of life can also be affected by some other conditions connected to the diagnosis and treatment of brain tumours, including anxiety and depression. In turn, anxiety and depression make it more difficult to adjust to the diagnosis and cope with the changes associated with having a brain tumour.

Living with a brain tumour can be very challenging for everyone involved, regardless of the type or severity of the tumour. Being aware of the early signs of mental health problems is important so that those affected can get the right treatment.

What are brain tumours?

Primary brain tumours develop from brain cells and can be either benign (non-cancerous) or malignant (cancerous). Generally, benign tumours remain in the part of the brain in which they started, which can be problematic depending on the location, while malignant tumours can spread into the surrounding brain tissue. Both types of tumours can cause pressure and damage to the brain. The cause of most primary brain tumours is unknown. Secondary brain tumours can occur when cancer cells from other parts of the body spread to the brain.

Around 1,400 Australians are diagnosed with a malignant primary brain tumour each year.[1] Although primary brain tumours account for less than 2 per cent of cancers in Australia, they can impose a large burden on individuals, families and carers.

Treatment usually involves surgery to remove as much of the tumour as possible, generally followed by radiotherapy and/or chemotherapy.

Benign tumours can be as difficult to treat as malignant tumours, depending on their location within the brain and whether surrounding brain tissue could be damaged by surgery.

Treatment for primary brain tumours may start very quickly, which means the person affected and his or her family and friends may have little time to come to terms with the diagnosis before treatment begins.

There are many types of brain tumours and the likely outcome varies, depending on the type and grade of tumour. Many tumours are treatable, while others are controllable for years.

Some tumours respond to treatment initially, but have a tendency to come back. Therefore, many people with brain tumours have to adapt to living with the effects of the tumour, its treatment and the threat of a recurrence.

While some people with a brain tumour make a complete recovery after treatment, most require some support and care in the following years, particularly from relatives and friends.

The stress associated with giving this care can be considerable.

The effects of brain tumours

Brain tumours can cause a variety of symptoms. These can take the form of *neurologic symptoms* (e.g. headaches, dizziness, impairment of speech or movement), *cognitive changes* (e.g. memory problems) and *behavioural changes* (e.g. changes in the way people think or act). These effects can be due to the brain tumour itself, or to surgery, medication (such as steroids which are commonly used to reduce swelling in the brain), or other treatments such as radiotherapy or chemotherapy.

Changes can be short-term or lifelong, may get better or worse over time and may include:[2]

- **Anger** – showing verbal aggression, acting in physically aggressive ways, being annoyed easily or being impatient
- **Attention and concentration** – being disorganised or having trouble doing two or more things at the same time i.e. multi-tasking
- **Communication** – interrupting the conversation or talking out of turn, having trouble finding words
- **Confusion or disorientation** – not knowing where you are, who you are or what day it is
- **Self-focus** – focusing on your own needs, feelings and circumstances, having less ability to empathise with others, being insensitive to the needs or concerns of others
- **Problem-solving and organisation** – having difficulty with tasks such as planning and seeing the consequences of actions,

www.beyondblue.org.au ☎ 1300 22 4636 1

www.beyondblue.org.au/resources

BRAIN TUMOURS, ANXIETY AND DEPRESSION

ADVICE FOR FAMILY, FRIENDS AND CARERS

Excerpt from a Fact Sheet developed by BTAA and beyondblue on Brain Tumours, anxiety and depression.

When a person has a brain tumour and anxiety or depression, it can affect family members and friends. People who support and care for someone with anxiety and/or depression may be at increased risk of developing anxiety and/or depression, so it's important that you look after your own health.

- Make sure you eat well, exercise regularly, get enough sleep and avoid alcohol and other drugs.
- Allow yourself time to relax and do what you enjoy.
- Look out for symptoms of anxiety and depression in yourself and seek help at the earliest sign.
- Seek support from professionals.
- This may involve having counselling or attending a support group.
- Find ways to ease the load, for example take Carer's Leave from work.
- Involve other family members and friends and accept offers of help.

BRAIN TUMOURS ANXIETY AND DEPRESSION

- Acknowledge you are going through a difficult time and are likely to experience periods of grief.
- Remember that allowing others to help is not a sign of weakness - rather it is an act of generosity to allow them to show their concern and support for you.
- For more information, see The ***beyondblue*** guide for carers booklet at *www.beyondblue.org.au/resources*

This newsletter was produced with the assistance of Roche Products Pty Ltd

Editor **Susan Pitt, BTAA**

Designed by **Jon Shirley Creative**

Printed by **Mavericks Print**

Authorised by Matthew D Pitt, Chair, BTAA PO Box 76, Dickson, ACT 2602

2014 DIARY DATES

30 MAY – JUNE 3, 2014

ASCO, Chicago.

www.am.asco.org/key-dates

www.trog2014.com

ALL YEAR

IBTA Walk around the World for Brain Tumours.

The World. www.theibta.org.

4 – 5 MARCH

COSA Cancer Care Coordination Conference, Sydney

www.cosaccc2014.org

7 MARCH

Neurosurgery Network Allied Health Professional Brain Tumour Awareness Day

www.aci.health.nsw.gov.au/events/brain-tumour-awareness-day

17 – 19 MARCH

The Society for Brain Mapping and Therapeutics, and The Brain Mapping Foundation, Sydney.
www.trog2014.com

1 – 4 APRIL

TROG 26th Annual Scientific Meeting, Sunshine Coast.
www.trog2014.com

27 APRIL – 3 MAY

Brain Cancer Action Week. Australia.
(Includes Patient Forum Sydney 1 May CHECK date)

7 – 9 MAY

The Australasian Neuroscience Nurses Association Scientific Conference, Canberra.

Emaill: ConferenceConvenor@anna.asn.au

27 JUNE

NNPDSC 11TH Annual Conference, Sydney NSW
Neurosurgical nurses event.

www.aci.health.nsw.gov.au/events/neurosurgical_nursing_professional_development_scholarship_committee

28 JUNE – 2 JULY

16th International Symposium of Paediatric Neuro-Oncology, Singapore

JULY

ACT BT support group stall at the opening of ACT Cancer Centre

24 AUGUST

BTAA AGM. Canberra

2- 4 OCTOBER

Neurosurgical Society of Australasia (NSA)
Annual Meeting Perth

www.nsa.org.au/documents/item/233

26 OCT -1 NOV

INTERNATIONAL BRAIN TUMOUR AWARENESS WEEK

24- 25 OCTOBER

7th COGNO ASM Melbourne
http://www.cogno.org.au/content.aspx?page=cognoasm-home

13 – 16 NOV

19th Annual Scientific Meeting of the Society for Neuro-Oncology (SNO 2014), Miami, Florida.

2-4 DEC

Clinical Oncology Society of Australia (COSA)'s 41st Annual Scientific Meeting, Melbourne.

www.worldcancercongress.org/cosa-annual-scientific-meeting-0

3-6 DEC

WORLD CANCER CONGRESS, MELBOURNE