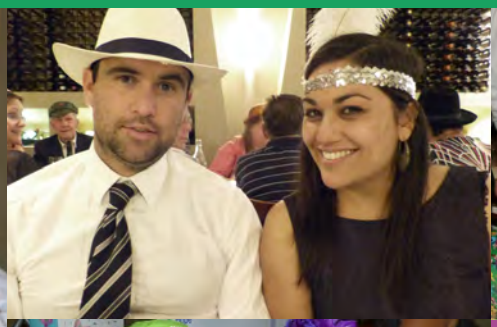
BRAIN TUMOUR ALLIANCE AUSTRALIA Inc.

International Brain Tumour Alliance Week Edition

26 OCTOBER TO 1 NOVEMBER 2014

This newsletter was produced with the assistance of funds from ***Sarah Mamalai's Brainstorm for a Cure***



INSIDE THIS ISSUE

LETTER FROM THE CHAIR

Welcome to this special edition to mark International Brain Tumour Awareness Week | 26 October to 1 November 2014.

In this issue we showcase many of the organisations attending the 2nd BTAA National Summit of Brain Tumour Advocates in Melbourne.

The BTAA Summit's theme is 'Towards a National Plan for Brain Tumour Advocacy'. Strong consumer advocates from across Australia will come together – all motivated by the need to salvage and build from what is bad and destructive – the diagnosis of a brain tumour. Special thanks to the **Cure Starts Now** – our sponsor for 2014. Also thanks to the **Cure Brain Cancer Foundation** for assistance with facilitation.

Our Summit follows the 7th COGNO Annual Scientific Meeting on 24 and 25 October - http://cogno.org.au/content.aspx?page=cognoasm-home COGNO's ASM theme for 2014 is 'Translating science to patient centred trials'.

This issue also includes an article on **fatigue** – a common side effect of brain tumours.

Congratulations to BTAA's co-founder **Denis Strangman**, the 2014 recipient of the Public Service Medal awarded by the US Society of Neuro-Oncology (SNO). The award recognises Denis's remarkable contribution, including assisting some of the world's most marginalised and powerless people as Founding Chair of the **International Brain Tumour Alliance**.

Congratulations also to **Mary Anne and Michael Rosier** – first time grandparents to Oliver David Bartholomew – born in February 2014. Read about Mary Anne's many projects including the **paediatric project** and our main fundrasier **Wear a Hat for a Day for BTAA** below. Mary Anne is also the primary contact for BTAA's Freecall number **1800 857 221**. Mary Anne and Michael Rosier (a paediatrician) attended ISPNO in Singapore in June on behalf of BTAA.

CONTINUED PAGE 2

ABN 97 733 801 179 | Incorporated in the ACT: AO45837 | Freecall number 1800 857 221

LETTER FROM THE CHAIR

CONTINUED FROM PAGE 1

Please spread the word that BTAA provides educational grants to enable allied health professionals to attend events within Australia and internationally, with assistance from the **Nicola Scott** educational trust. Read grant recipient **Michelle Rosano's** report on ISPNO below.

Finally a big thanks to our **committee** – remember we are all unpaid volunteers. We are focusing on building links so we can better serve our community of health consumers and health professionals.

Thanks to a grant by **Glaxo Smith Kline (GSK)** we have a new web site will make it easier for us to provide relevant information for those who need it when they need it. It will also make it easier for our supporters to donate to BTAA to enable us to support those diagnosed with a brain tumour. Visit **www.btaa.org.au** to sign up for our e-news, donate to BTAA and more.

Matt

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

DURING 2013-14 BTAA

Excerpt from the AGM Chair's Report mailed to members: The total number of calls to Freecall **1800 857 221** was **456** [free from landlines], excluding follow up calls. This service enables newly diagnosed persons or their family to speak to someone who has experience with the brain tumour journey, Trained counsellors listen and refer callers to available support services: their nearest face-to-face support services and/or the **Cancer Council's Cancer Connect service**).

BTAA also obtained additional copies of the American Brain Tumour Association 'Primer' on brain tumours and imported and mailed it as part of an information kit to around **250** patients and caregivers at BTAA's expense. Our mailing list now has over **1,800** supporters who received this newsletter free twice in the year and frequent **e-news** Chair. We now have over **1,400** followers on Facebook.

BTAA also obtained funding from the John James Foundation to enable the importation and distribution of a resource for paediatric brain tumour patients and their families and associated promotional materials.

BTAA's revenue exceeded **$100K**, double the revenue in the previous year.

BTAA's Annual General Meeting elected two new committee members – **Anita Berghout** from Newcastle and **Rigoula Rousakiss** from Melbourne. The rest of the committee was returned unopposed. **Matt Pitt** remains in the Chair, **Kelly Webster** continues as Vice Chair, **Catherine Hindson** as Treasurer, **Susan Pitt** as Secretary and **Mark Dalliston** and **Denis Strangman** as committee members. **Mary Anne Rosier** stepped up to be Assistant Secretary.

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

FATIGUE, CAUSES AND MANAGEMENT

By Matt Pitt

Fatigue is a very common side effect of having a brain tumour. Here is an excerpt from my notes from a presentation on fatigue at the 2013 Society for Neuro-Oncology (http://www.soc-neuro-onc.org/) Annual Scientific Meeting. The presentation by Christine Miaskowski. School of Nursing, University of California, San Francisco, California, USA was titled: **'Fatigue, causes, and management'**: Christine said:

"I'll soon have been a neurooncology nurse for 40 years, and I have been confronted by the challenge of controlling fatigue in these patients throughout this time. Despite being a very common problem, the evidence for managing fatigue in oncology patients in general is not extensive. It is also a misunderstood symptom. I will be so bold as to say I aim to raise your consciousness a bit in trying to understand the symptom. I think fatigue in terms of research is about ten years behind pain in terms of understanding its complexity. I am going to suggest to you that we are not measuring fatigue correctly. We are going to talk about mechanisms, and I hope to show you that fatigue is not a simple story. The wide intra-individual variability on this symptom is a problem. Fatigue occurs (along) the illness trajectory.

It can occur prior to starting treatment, and it can persist for many years after treatment. Cranial irradiation is the one of the most common causes of fatigue in brain tumour patients. I can tell you that in a study with 200 patients of all cancer types, we only recruited seven patients with brain tumours. The main reason the others we approached didn't agree to participate in the trial….they were too fatigued! In the study, the driving force for morning fatigue in the 200 patients was depression. The driving forces for evening fatigue was whether they had children, and going shopping. Let me show you why we are having trouble understanding this symptom: [Ed Note: Charts presented showed huge intra-individual and temporal differences in fatigue].

The USA National Comprehensive Cancer Network definition of cancer related fatigue is: '…a distressing persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.' [Ed Note: See www.nccn.org/professionals/physician_gls/f_guidelines.asp#supportive]. The key underlying concept of the definition is that the cancer related fatigue must interfere with function. The ICD-10 definition of fatigue is really challenging for doctors to use, because it just goes on and on:

'The following symptoms have been present every day or nearly every day during the same 2-week period in the past month:

A. ***Significant fatigue,*** *diminished energy, or increased need to rest, disproportionate to any recent change in activity level, plus five or more of the following:*

1. *Complaints of generalized weakness, limb heaviness.*
2. *Diminished concentration or attention.*
3. *Decreased motivation or interest to engage in usual activities.*
4. *Insomnia or hypersomnia.*
5. *Experience of sleep as unrefreshing or non-restorative.*
6. *Perceived need to struggle to overcome inactivity.*
7. *Marked emotional reactivity (e.g., sadness, frustration, or irritability) to feeling fatigued.*
8. *Difficulty completing daily tasks attributed to feeling fatigued.*
9. *Perceived problems with short-term memory.*
10. *Post exertional fatigue lasting several hours.*

B. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. There is evidence from the history, physical examination, or laboratory findings that the symptoms are a consequence of cancer or cancer therapy. *The symptoms are not primarily a consequence of co morbid psychiatric disorders such as major depression, somatization disorder, somatoform disorder, or delirium."*

These criteria can be found at:

www.cancer.gov/cancertopics/pdq/supportivecare/fatigue/HealthProfessional/page4].

For a copy of my notes email **chair@btaa.org.au**

Wear a Hat for a Day for BTAA

By Mary Anne Rosier

Thanks to all the people who have registered for BTAA's Hat Day this up and coming International Brain Tumour Awareness Week, 26th Oct - 1st Nov,2014.

BTAA has chosen this week to have its annual fundraiser and awareness raiser. By having a Hat Day for BTAA you are raising awareness in the community, about the brain tumour illness, plus, you are helping BTAA reach more people. BTAA can only assist people if they know our organisation exists. BTAA is the only national support and advocacy organisation, in Australia, for the brain tumour patient and their carers/ loved ones.

Well Deserved Recognition for Denis

By Susan Pitt

The following is an excerpt of a BTAA media release:

'BTAA co-founder Denis Strangman has been selected by the US-based Society for Neuro-Oncology (SNO) for its 2014 Public Service Award. It is believed that this is the first time an Australian has been selected for an award by SNO. The President of SNO, Dr David Reardon, advised Mr Strangman: "This award recognizes a meritorious individual who has made significant contributions to the field of neuro-oncology. There is no doubt that you have had a global impact on our entire field during your tenure as chair of the International Brain Tumour Alliance. Thanks to your efforts, the IBTA has had a tremendous impact on advancing brain tumor [ed: US spelling] advocacy worldwide, and you leave a lasting legacy for which patients, caregivers and professionals shall always be grateful."

Denis has been a patient advocate on behalf of brain tumour patients and their carers since the death of his wife Margaret in Canberra from a malignant primary brain tumour in 2001. He has travelled the world to meet with fellow advocates and patients and carers in many countries to encourage and support them in their work. He was the inaugural secretary of Brain Tumour Alliance Australia (BTAA) and remains on its Committee and in 2005 co-founded the International Brain Tumour Alliance (IBTA), retiring earlier this year as its Chair.

The Award will be presented at the Society's Annual Scientific Meeting to be held at Miami, USA, later this year, and will be accepted on Mr Strangman's behalf by Dr Helen Wheeler from Sydney, who is one of Australia's leading oncologists specialising in brain tumours. Mr Strangman said that the Award was a recognition of the role of patient advocates in supporting brain tumour patients, carers and families and also a tribute to the IBTA and his IBTA co-founder, Mrs Kathy Oliver, of Surrey in the UK, who lost her son aged 32 to a brain tumour in 2011.'

Denis Strangman at the Cancer Centre open day

A Gift from BTAA for families with a child with a BT

By Mary Anne Rosier

A particular focus for BTAA in 2014 has been around paediatric brain tumours. Thanks to funds raised from Peter Vanzwan and the Vanzwan Golf Day, together with a recent grant from the John James Foundation, BTAA is now better able to support families with a child with a brain tumour.

Earlier in the year I represented BTAA at the **International Symposium on Pediatric Neuro Oncology (ISPNO)** in Singapore, building our networks with many organisations involved in paediatric brain tumour research and support. My partner Michael Rosier, a paediatrician also represented BTAA and his report was in the *BTAA e-news* following the summit.

BTAA has now imported a paediatric brain tumour handbook developed by the Brain Tumour Foundation of Canada to include in a package customised for each family. We also include an age appropriate gift for the child and their siblings. Together with **Catherine Hindson** I am working with paediatric brain tumour care coordinators in all the centres treating children across Australia to enable us to reach every family with a child diagnosed with a brain tumour. Thanks to **Colin McCulloch** and **Bartercard** for support with the posters.

To receive this handbook phone BTAA's freecall number **1800 857 221** (Free from a landline only)

Or visit our website www.btaa.org.au and order online.

Travel Insurance

By Denis Strangman

As part of its advocacy responsibilities BTAA has presented a case to the Insurance Council of Australia seeking the extension of travel insurance coverage for pre-existing medical conditions, particularly for those who have a brain tumour.

BTAA is seeking support for its stance from other brain tumour groups and relevant professional societies.

Some people with certain cancers e.g. breast and prostate have been granted coverage but not those who have ever had a brain tumour. They are usually put through a number of questionnaires but the result is always the same - No!

In one case an insurance company flatly refuses to cover anyone who has ever had brain surgery - regardless of the original reason for the surgery or the number of years since the operation.

We know of several insurance companies in the UK that extend travel insurance coverage to UK residents who plan to travel. Why can't this be the situation in Australia?

Readers who have experienced difficulties in this area should contact the BTAA Freecall number 1800 857 221 or email enquiries@btaa.org.au.

BTAA EDUCATIONAL GRANTS

By Susan Pitt

Ensuring all patients have access to a brain tumour care coordinator remains BTAA's number one priority. Catherine Hindson of BTAA oversees the new BTAA educational grants program.

This program enables allied health professionals involved in health care coordination who are members of BTAA to increase their participation in educational events. BTAA provides grants within Australia of $500 and internationally of $1,500, with the assistance from the **Nicola Scott** educational grant trust. The purple butterfly is the symbol the BTAA educational grants in her memory. Contact treasurer@btaa.org.au for information on the grant criteria.

Grant recipients Elizabeth Bland and Michelle Rosano received grants to attend the 16th International Symposium on Paediatric Neuro-Oncology (ISPNO) in Singapore from 28th June – 2nd July, 2014. Read Michelle's report below.

Nicola Scott.
www.btaa.org.au/nicola-scott.html

Michelle Rosano Reports on ISPNO

I recently had the opportunity to attend the 16th International Symposium on Paediatric Neuro-Oncology (ISPNO) in Singapore thanks to the Nicola Scott Education Grant.

I have only worked in the field of neuro-oncology for the past twelve months, prior to that I have over ten years of paediatric oncology experience. One thing I have found working in this field is that compared to other childhood cancers such as leukaemia, there is a much lower cure rate for children with brain tumours. After attending ISPNO it has become apparent that while we still struggle to cure brain tumours in children, there is a lot of research going on around the world with the hope of improving these statistics.

I arrived in sunny Singapore on the Saturday evening ready to attend the Education Meeting the following day. The Education meeting was associated with 8th St. Jude-Viva Forum in Paediatric Oncology which was on just prior to ISPNO. There were some great lectures looking at the origins of paediatric and adult cancer and the current management of paediatric brain tumours including practical, supportive and multidisciplinary care as well as the medical management. I found all the lectures interesting, but I would have to say the one that stood out for me was looking at integrated palliative care practices to improve the quality of paediatric oncology care. While this presentation was in relation to general paediatric oncology as opposed to neuro-oncology,

(L-R) Liz Bland, myself, Michele Casey, Mary Anne Rosier & Geraldine Callan.

I felt it was something that directly related to neuro-oncology. It was presented by Dr. Justin Baker who is a paediatric oncologist as well as a palliative care physician at St. Jude's Children Research Hospital. The main discussion was around the introduction of palliative care early in the course of the illness and the role it could play regardless of the prognosis for children with metastatic cancer or a high symptom burden with the goal of "adding life to the child's years, not simply years to the child's life". I think that given the lower survival rates and the symptom burden of paediatric brain tumours, the early introduction of palliative care could greatly benefit these patients. It isn't done to take away hope, but to add hope despite the expected outcome.

Another highlight of the first day was the International Nurses Lunch. We were given set seats with nurses from various parts of the world. It was great to hear about the different practices of nurses around the world and the amazing things that the nurses from undeveloped countries have achieved despite their limited resources. It certainly puts things into perspective! Following the Education Meeting we had a welcome reception where I finally met the lovely Mary Anne Rosier and her husband, Michael.

Mary Anne and Michael Rosier

The second day, which was the first official day of ISPNO, looked at the biology of Medulloblastoma and then at the clinical aspects of treating the disease. There has been some great work around Medulloblastoma and it looks like they are getting close to some targeted treatments based on the molecular profile of the tumour. There was some interesting discussion around whether improving long-term quality of life in fewer neuro-oncology survivors was preferable over a higher overall survival rate. It was an interesting debate with not a clear decision being made. That evening I met with Mary Anne, Michael and Liz and we headed into China Town to meet up with some lovely people who are involved in a similar organisation to BTAA offering support to people affected by brain

Australian Neuro-Oncology nurses at the Gala Dinner.

cancer. I was fortunate to spend the evening talking with a social worker who works with the organisation. He is doing a wonderful job of providing support to the patients and their families with very limited resources.

Day three we looked at High Grade Gliomas and Diffuse Intrinsic Pontine Gliomas (DIPG). There is ongoing research into DIPG, but it is apparent that a lot more funding needs to be put into research as well as looking at the implementation of an international database. It is clear that a lot of work needs to be done to increase the cure rate of DIPG!

The afternoon was spent on the nurses program. There were some wonderful speakers from different European and North American centres as well as some from Australia. There are some interesting nursing research projects underway and there was a lot of discussion around the possibility of a national or international research project. Something for us all to go home and think about.

We had the Gala Dinner that night which was a fantastic opportunity to meet and socialise with other delegates.

The final day was aimed at survivorship and quality of life. There was a strong focus on the cognitive deficits of survivors of paediatric brain tumours and some talk about the potential benefits of proton therapy. Interesting to see where this goes!

I found ISPNO to be refreshing and it shows us that there is ongoing work being done to increase the survival rate of children with brain tumours. While the focus is on increasing survival, there is also a strong focus on quality of life associated with increased survival. I look forward to hearing what changes have been implemented at ISPNO in Liverpool in 2016.

Thank you once again to BTAA and the Nicola Scott Education Grant for giving me the opportunity to attend this conference.

BTAA'S NEW WEBSITE

BTAA has a new web site developed by Nigel Hokin and the team at Engonet. www.engonet.com

BTAA's Kelly Webster and Mark Dalliston worked with Nigel and Engonet to finalise the design and functionality. The new site provides greater emphasis on information and new functional areas e.g. Events, Get Involved and integration with our social media presence. It also promises ease of maintenance for BTAA's volunteer site administrators.

Thanks to GSK which provided independent funding which has been put to the development of the new website for BTAA. GSK is a global pharmaceutical healthcare company which has been operating in Australia since the early 1900's.

engonet

BOOK REVIEW

"Lemon-Sized Tumour"

Author: Jenny Overton

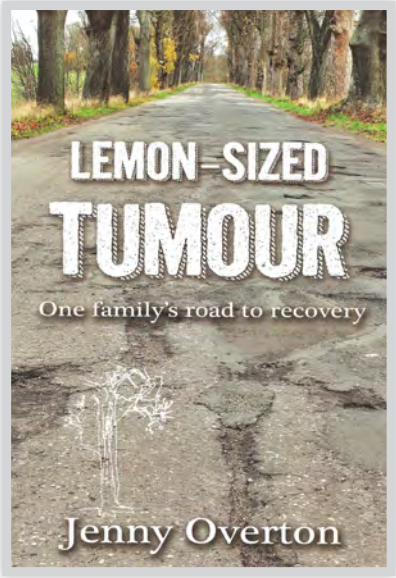
Even Before Publishing

(www.evenbeforepublishing.com)
123 pps. 2014. ISBN 9781921632976
(p'back).

Brain and tumour. Two of the worst words to go together in one sentence. This book follows the personal journey of a mother whose eighteen year old son faces this diagnosis. The story journeys through the medical events, the discovery of what an Acquired Brain Injury means, the grief and the aftermath of this event that shattered their lives. This is a very honest account covering a seven year period of a family's life when facing some tough, ongoing hardships. Woven throughout are lessons and insights of faith in God that give hope and perseverance in difficult times.

Review by Denis Strangman

This is a wonderful book by a Faith-filled mother as she and her family travel with her son from 18 to 25 years of age after he is diagnosed and recovers from a pilocytic astrocytoma brain tumour – a so-called "best case tumour", as she was informed. It is the story of a brain tumour survivor and his family and is fairly rare within the non-scientific literature of brain tumours because so often the published stories are about someone who has lost their fight or they and their carers are dealing with a more malignant primary brain tumour, such as a glioblastoma multiforme (GBM). Jenny Overton's journey will provide great insights for the carers of a person newly diagnosed with any one of the 120 different types of brain tumour.



AVAILABLE ONLINE.
See www.lemonsizedtumour.com.au

MONKEY IN MY CHAIR

The Cure Starts Now's innovative program to help seriously ill children stay connected to their friends and school. Kit includes:

Monkey – This big soft monkey will fit right into your child's seat at school.

Backpack – This bag can be used to send items (notes, pictures, homework) back and forth between your child and their classroom.

Book –The book is a great way to explain to your child's classmates about the monkey.

Journal–The journal may stay in the classroom for their classmates to write notes in or accompany your child to write about their experiences.

Photo Album –You can fill this with photos of your child's journey to share with the class or leave it with the teacher to fill with photos of the monkey.

Mini monkey –This miniature version of the big monkey can stay with your child so that they are not without a monkey.

Teacher Companion –This is a book that the teacher can use in the classroom. It has resources and lesson plans as well as ideas about how to use the monkey in the classroom.

Other Fun Items –We also include many other fun items for your child to enjoy.

Monkey Message online – The program also offers each child and their classroom online access to "Monkey Message". This is a fun and easy way to communicate electronically. They can send notes and pictures back and forth. The feature also offers the teachers new ideas and activities to use in the classroom.

How do you get one?

For an easy to complete application form please contact:

The Cure Starts Now (Australia) MIMC Coordinator:

Diane Marthick

Mobile: 0400 745 262

Email: monkey@TheCureStartsNow.org

Monkey In My Chair is a Cure Starts Now initiative. Please visit our website to learn about other family support and assistance opportunities at www.thecurestartsnow.org/au or email us at monkey@TheCureStartsNow.org

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

The Cure Starts Now

By Ren Pedersen

One particular brain tumour has been defined in medical circles as "The Deadliest Cancer Known To Man". Paediatric Diffuse Intrinsic Pontine Glioma (DIPG) sadly claims medicine`s most obscene trifecta: NO screening, NO prevention and NO effective, long term treatments, let alone cure: www.youtube.com/watch?v=zwYYtw1sgow&feature=kp

"Eminent brain tumour specialists and researchers are now realising that by advancing DIPG research, a myriad of positive applications for all brain tumours and cancers will eventuate." states Ren Pedersen, Director of The Cure Starts Now (Australia): **www.facebook.com/TheCureStartsNowAustralia**

In 2011, The Cure Starts Now united many of the world`s leading foundations and institutions and established brain tumour`s ultimate 'War Council': the DIPG Collaborative (**www.dipg.org**).

All brain tumour organisations wanting to advance their scope would be well served to consider joining this amazing and proactive brain tumour coalition. So many exciting new research projects will be fast tracked with more Australian institutional and foundational involvement.

"No individual charity or institution should think that it holds all the aces. Together, let`s throw a wider net and find cures for all brain tumours. Together, lets target the most impenetrable and toughest tumours known to science, within an all encompassing, totally transparent and open Collaborative.", Ren adds.

Until just 3/4 years ago, DIPG was not even a recognised, stand alone, illness in Australia. Thankfully, things really are warming up: **http://www.abc.net.au/local/stories/2012/02/06/3424007.htm**

CSN`s informal BT/DIPG support assistance is rapidly expanding and our national Monkey In My Chair program (www.facebook.com/TheCureStartsNowAustralia/posts/430669327038847) is now being embraced by a number of highly reputable Australian entities, ie Victorian Education Dept and Ronald McDonald House, etc. Feel free to let families/friends of any seriously ill children your organisation comes into contact with, know that many positive outcomes derive from this newly implemented Australian initiative, ie: **www.youtube.com/watch?v=SEqH37oK2uo**

Vale Erin Griffin. Powerful image Amanda.

The Cure Starts Now enthusiastically supports the fine work of the Brain Tumour Alliance Australia.

Ren Pederson Ph: 1300 265 206

BTAA thanks The Cure Starts Now for support for catering for its Summit.

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

Cure Brain Cancer Foundation Update

We recently closed our research funding rounds for 2014. We have been delighted with the response and are eagerly awaiting assessment by our Scientific Advisory Committee (SAC)!

Our objective is to increase quality brain cancer research activity and the number of clinical trials in Australia. We aim to increase survival (and fulfill our mission) and to actively encourage multi-disciplinary collaboration.

There are four categories of grants currently available: innovation, collaboration, clinical research and The Tony Lucas Grant. We have received 39 applications from groups across Australia. Applications are focused on both paediatric and adult brain cancer across multiple tumour types, both adult and paediatric. Successful applicants will be announced at the end of October.

Our world-class Scientific Advisory Committee will advise on research funding and policy decisions. SAC members are selected on the basis of academic and/or medical excellence, history of breakthroughs and their commitment to accelerating treatments to children and adults with brain cancer. The strength of our SAC demonstrates our commitment to responsible spending and good governance. It also highlights our desire to fund the best research with the highest chance of success. Time is of the essence!

CBCF Scientific Advisory Committee members

Dr Mustafa Khasraw, Geelong Hospital; Prof Mark Rosenthal, Royal Melbourne Hospital; Dr Helen Wheeler, Royal North Shore Hospital; Prof Jan Buckner, Mayo Clinic; Prof Web Cavenee, University of California San Diego; Prof Inder Verma, Salk Institute. Individual bios can be accessed on our website at www.curebraincancer.org.au

New projects that have been funded this quarter include:

- A Queensland Tissue Bank at the Wesley Hospital
- The John Trivett Fellowship in Brain Cancer at the Queensland Brain Institute and Institute of Molecular Biology – recruitment will be underway shortly
- Support for Professor Brandon Wainwright, Institute of Molecular Biology
- A project in DIPG undertaken at the Children's Cancer Institute of Australia, Sydney

BTAA thanks the Cure Brain Cancer Foundation for facilitation assistance for the Summit.

James Crofts Hope Foundation

The James Crofts Hope foundation was formed in February 2001 in Perth in memory of James Crofts. It is a licensed and registered charity dedicated to assist brain tumour sufferers in Australia and to support their carers and family and any way they can.

www.jamescroftshopefoundation.org.au

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

Brisbane Brain Tumour Support Group

By Dianne McGinn

When you are dealing with a brain tumour it truly shakes up your world - and your mind. As a person you can often find things starting to happen or no longer happen like before - emotionally, physically and mentally. It brings about changes, challenges and questions? Am I normal?

Support can be plentiful at the start, but when you look OK, friends, family, work mates and even some medical staff don't quite understand. That's where a tumour support group can be helpful.

Meeting other suffers and carers in a casual setting to listen, share experiences and knowledge may help you in dealing with the "new you".

The Brisbane Brain Tumour Support Group came about when the Brain Tumour Support Service with Cancer Council Queensland (CCQ) asked if a group was needed and wanted. A group of four people seeking support themselves felt it was. With the help of CCQ and health care professionals we are trying to provide a service that Brisbane has been lacking for several years, and our first meeting was held in June this year.

The meetings are held on 1st Thursday of each month (except January) at 10am – 12noon. Run independant of CCQ but greatly supported by them, the meetings are held at the CCQ building on 553 Gregory Terrace Fortjiude Valley. No appointment is necessary and it is free to attend. Limitedly parking is available under the building. Tea and Coffee is provided.

Guest speakers are featured at some meetings and the talks are from professionals such a dieticians, exercise physiologists and psychologists. Talks last about 45 mins to allow plenty of time to mingle.

For further information regarding the Support Group, please email Braintsg@gmail.com or you can contact the CCQ helpline on 131120 for more information.

We welcome any patient with any brain tumour, carers or loved ones along. We are here to share and support.

Brain Tumour Association of Western Australia

The Brain Tumour Association of WA (BTAWA) was established in late 2007 after a group of family and friends came together to organise a WA event as part of International Brain Tumour Awareness Week.

Previously, no formal structure existed which enabled those newly diagnosed to share and learn BTA WA is building a network of people. Like the wider community, members come from all walks of life, but share a common experience and understanding. Our key aims are:

To provide a support network for patients, their families and friends.

To offer a local contact point for obtaining information regarding brain tumours, as well as links to the latest national and international research.

To be a strong advocate and voice for patients and families in WA

BTAWA Brain Tumour Awareness Week Morning Tea and Speaker Tuesday 28th October See our BTAWA website for details: www.btawa.com.au

BTAWA Brain Tumour Association of WA

Contact us on 08 6314 6680

E: info@btawa.com.au

W: www.btawa.com.au

BTAWA will be represented at the Summit by John Crofts, Secretary of the James Crofts Hope Foundation.

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

Gold Coast United Brain Tumour Support Group

The United Brain Tumour Support Group on the Gold Coast has been operating since 2006.

We meet at 10.30am on the third Wednesday of each month (except December and January) at the Tugun Surf Lifesaving Club with beautiful views of the incoming surf. Our website is www.braintumourhelp.com.au and Facebook is United Brain Tumour Support Group.

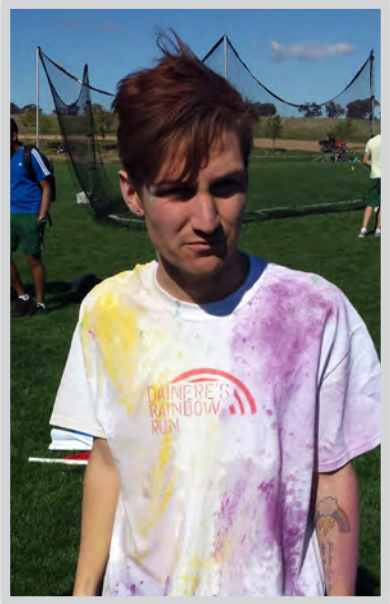
Contact: Peter McLaughlin

PO Box 1881,

Kingscliff NSW 2487

Mobile: 0422 784 885

Email: petershark72@hotmail.com



Students, teachers and friends (Above Top), Jarrett Anthoney (Above) after the Inaugural Dainere's Rainbow Run (a colour run) for the Burgmann Anglican School Year 12.

Dainere's Rainbow

By Yvonne Anthoney

Dainere's Rainbow Brain Tumour Research Fund was established in conjunction with The Sydney Children's Hospital Foundation to assist the research team lead by Dr David Ziegler; research will be undertaken on three research projects as part of Dainere's Fund. This is a not for profit fund and 100% of all funds raised or donated go directly to this vital research.

Dainere's Rainbow Brain Tumour Research Fund maintains a lifetime commitment to helping eradicate this number one cancer cause of death in children. We are dedicated to raising awareness of paediatric brain tumours and raising money to fund research in memory of our most precious Dainere and hopefully seeing her greatest wish in life become a reality.

On Dainere's website you will find information about Dainere, fundraising events, research progress and how you can make a difference to help the cure come about.

Each and every day we are working to raise as much awareness within the community as possible.

We thank you for your interest and generosity.

The Anthoney Family

Dainere's Rainbow is an apology for the Summit but hopes to attend next one.

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

Peace of Mind Foundation

By Rebecca Picone

Peace of Mind Foundation (PMF) was established in December 2013 to help improve quality of life for brain cancer patients and their families through the provision of financial, emotional and practical support.

The PMF was created in response to a perceived gap in support networks and assistance for brain cancer sufferers all throughout Australia. Our desire is to offer a personalised service for patients and their families, starting at initial diagnosis and throughout the whole journey.

As we are in the early stages of development we are strategically focusing our services in Victoria only so that our current limited funding can have maximum impact for those families we are able to help. We have been actively supporting many families by providing financial assistance grants, in home support and linking patients/carers to other relevant support services within their community.

Our major focus in the next months is to launch support groups for patients with brain cancer and their families/carers in the Geelong and Wyndham areas (Victoria). These are key regions in Victoria we have identified as being void of services specifically for brain cancer patients.

We are also seeking support and volunteers to help us manage the many projects and fundraising activities we have planned for the near future. One of our major projects we wish to launch early 2015 is our 'Superbrains' Kids Club – an online club specifically for children battling brain cancer all over Australia.

For more information or to find out how you can get involved please email us on **info@peaceofmindfoundation.org.au** or visit **www.peaceofmindfoundation.org.au.**

PNET Cancer Foundation

Primitive Neuroectodermal Tumors of the Central Nervous System (CNS PNET) are identified as highly aggressive large tumours that are found in the brain and spine. The PNET Cancer Foundation is a not for profit organisation that is focused on increasing research into CNS PNET cancer. The Foundation aims to raise awareness of CNS PNET cancer, become a global body of knowledge, and accelerate research to develop better treatments and an eventual cure. The Foundation has harnessed the international experts in the field, and we are working to co ordinate the PNET community, by supplying collective efforts and knowledge to achieve these objectives.

Contacts **Kerry Morrison** and **William Stark**, **www.pnetcancerfoundation.com**

Grey Matters

Grey Matters is a support group for those living with benign and low grade brain tumours and is affiliated with Cancer Council Victoria and associated with Melbourne Hospitals (including Royal Melbourne and The Austin). We meet on the 3rd Monday of the month at the Carlton North Library at 7pm for 7:30pm.

Contact **Janet Micallef** and **Samantha Wright.**

info@greymatters.org.au
www.greymatters.org.au

Brain Tumour Ahoy

Samantha Wright's online support group for low grade tumours. www.braintumourahoyhoy.org

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

The Isabella and Marcus Fund

The Isabella and Marcus Fund mission is to fund Australian research into paediatric brainstem tumours with a focus on Diffuse Intrinsic Pontine Glioma (DIPG). Rob & Khush, Isabella's parents recently climbed Africa's tallest mountain to raise money to continue funding for 3 research projects in 2015.
The next event is 15 November 2014 and closer to home - a scenic walk along the Yarra River and Mullum Mullum creek AND raise money for PhD scholarships for DIPG. 50km and 20km walks to choose from. All funds, including registration, will go to The Isabella and Marcus Fund. See more details on their web site.

www.isabellaandmarcusfund.org.au

Young brain cancer patient Ashlee with her 'in home' music therapist, Cherie.

Robert Connor Dawes Fund

The Robert Connor Dawes Fund was founded in July 2013 in memory of 18 year old Connor Dawes who passed away in April 2013 from ependymoma brain cancer.

The fund is using Connor's initials "RCD" for its areas of focus: Research Care & Development. Connor received weekly in home music therapy during his illness. This was a highlight of all his therapies. The RCD Fund is now offering, as part of its "Care", music therapy to other young brain cancer patients across Australia.

The Robert Connor Dawes Fund Music Matters Grants

Music is more than just fun and relaxing, it can have a profound impact on our brains. Music therapy is the evidence-based use of music to accomplish individualised treatment goals. It can help with learning. For example, through its use of shared networks in the brain, music can target speech & motor deficits. It can help to improve memory and attention, as well as enhance psychological coping. Music therapy is non-invasive and is motivating, both of which help the heart sing and the brain heal.

We provide 10 private in-home music therapy sessions for children & young adults under 25 who have been diagnosed with a brain tumour, throughout Australia. A registered therapist is matched specifically to individual needs & location through a straightforward and confidential referral process.

Please visit: **http://rcdfund.org/music-therapy** for more information.

Liz Dawes

Executive Director

liz@rcdfund.org

0419 311 506

BTAA'S 2ND NATIONAL BRAIN TUMOUR ADVOCATES SUMMIT PARTICIPANTS

Talking Heads

Blackwood 8 have a Support Group called 'Talking Heads' for those affected by all types of brain tumours, those diagnosed, carers and friends aged approx. 25 -50yrs. Our purpose is to offer mutual support, education and resources in the local community. We meet every 3 weeks in Doncaster, Victoria. For further details contact Sally White or via the Blackwood 8 website. It is free to attend and supported by Vic Cancer Council and Manningham City Council.

Excerpt from the Talking Heads September 2014 Newsletter

"People usually consider walking on water or in thin air a miracle. But I think the real miracle is not to walk either on water or in thin air, but to walk on earth. Every day we are engaged in a miracle which we don't even recognize: a blue sky, white clouds, green leaves, the black, curious eyes of a child -- our own two eyes. All is a miracle."
Thích Nhất Hạnh

Talking Heads Counselling and Support:
Andrea: 0488 999 715

Email: sally@sallywhite.com.au Website: www.blackwood8.com.au

Facebook: https://www.facebook.com/

BrainLink

BrainLink Services Ltd (Melbourne) provides resources & information about services to people with Acquired Brain Injury, including people with brain tumours. We also keep a list of the support groups in Victoria, including our group in Blackburn for people with primary malignant tumours.

The Nerve Centre 54 Railway Road Blackburn
VIC 3130

Freecall: 1800 677 579 admin@brainlink.org.au

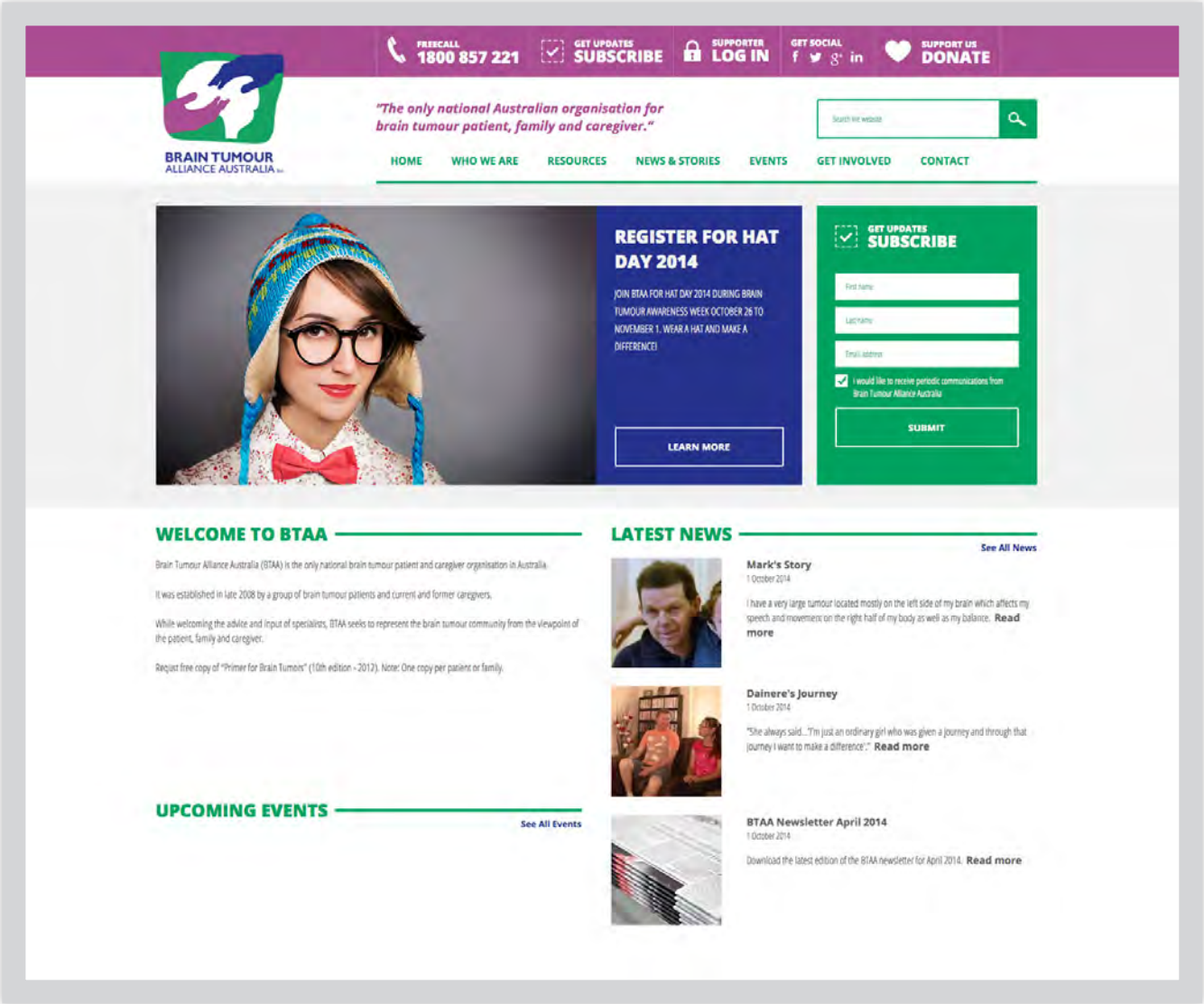
www.brainlink.org.au

CLINICAL TRIALS

The clinical trials Australia & New Zealand website is **http://www.anzctr.org.au/**, and it has a search function (**www.anzctr.org.au/TrialSearch.aspx**). For example If you type in 'glioblastoma', and select the trial status as 'recruiting', you'll get the result for recurrent glioblastoma (i.e., glioblastoma that has returned after the standard treatment of surgery and concurrent temozolomide and radiotherapy).

You can also use the Aus NZ Clinical trials site to indirectly search the USA government site, www.clinicaltrials.gov, or you can just go to that address and using the advanced search function, type in 'glioblastoma' and location 'Australia'. This will list ten active trials in recurrent glioblastoma that are currently recruiting and have trial sites in Australia. For more information speak to your health professionals about current and forthcoming clinical trials.
Email chair@btaa.org.au

SUPPORT BTAA



BTAA needs and appreciates your support. A donation of $25 enables us to provide a family with an information kit to help them find support and make treatment decisions.

You can:

Use the Everyday Hero Channel

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

Donate directly to BTAA.

CBA. BSB: 062 900

Account number: 10603153

Send a cheque made out to

BTAA to PO Box 76

Dickson, ACT, 2602

BTAA has been endorsed by the ATO as a deductible gift recipient.

Become a financial member of BTAA.

Entrance fee $20

Annual subscription $10 payable up to 5 years in advance.

Email **treasurer@btaa.org.au**

Or visit BTAA web site **www.btaa.org.au**

USEFUL LINKS

Brain Tumour Alliance Australia Inc www.btaa.org.au

Brain Tumour Australia Information www.btai.com.au

International Brain Tumour Alliance www.theibta.org

Virtual Trials www.virtualtrials.com

Clinical trials www.anzctr.org.au – search function

Clinical trials www.anzctr.org.au – see the search function

USA government site, www.clinicaltrials.gov

Brain Hospice www.brainhospice.com

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

The American Brain Tumour Association www.abta.org

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

The UK Brain Tumour Charity www.thebraintumourcharity.org/news

The Australian Cancer Research Fund www.brainfoundation.org.au

The Australian Genomics and Clinical Outcomes of Glioma (AGOG) www.agog.org.au

The Australian Pituitary Foundation www.pituitary.asn.au

The Brain Centre Collaborative www.monashinstitute.org/the-brain-cancer-discovery-collaborative.aspx

Brainstorm www.brain-surgeon.com.au/brainstrom.html

Blackwood 8 www.blackwood8.com.au

Brainlink Services Inc www.brainlink.org.au

Brizbrain and Spine Research Foundation www.brizbrain.com.au

The Cancer Council of Australia www.cancer.org.au

The Cancer Research Foundation www.acrf.com.au

The Children's Cancer Institute www.ccia.org.au

The Children's Leukaemia & Cancer Research Foundation (Inc) www.childcancerresearch.com.au

The Children's Research Foundation www.crf.org.au

The Cooperative Trials Group for Neuro-Oncology (COGNO) www.cogno.org.au

The Cure Brain Cancer Foundation www.curebraincancer.org.au

The Cure Starts Now - http://au.thecurestartsnow.org/

Dainere's Rainbow Fund - www.daineresrainbow.com.au/home

The James Crofts Hope Foundation www.jamescroftshopefoundation.org.au

The John Trivett Foundation now merged with CBCF (QLD) https://johntrivettfoundation.org.au/trivett-foundation-becomes-cure-brain-cancer-foundation-queensland/

The Kolling Foundation http://kolling.com.au

The Lowy Cancer Research Centre www.lowycancerresearchcentre.unsw.edu.au

The Make a Wish Foundation www.makeawish.org.au/netcommunity/sslpage.aspx?pid=1114&bm=-609293115

Neuro OncoloGy Information Network (NOgIN) www.sydneybrainandspinesurgeons.com.au/pdf/nogin-donation.pdf

The NSWCC Grey Matters and Brain Cancer Action www.braincanceraction.com.au/research/research-grants

The Peace of Mind Foundation www.peaceofmindfoundation.org.au

Redkite www.redkite.org.au

The Queensland Brain Institute www.qbi.uq.edu.au/research

Rare Cancers Australia www.rarecancers.org.au/

The Robert Connor Dawes Fund www.rcdfund.org

Royal Melbourne Hospital Neuroscience Foundation www.neuroscience.org.au

The Starlight Foundation www.starlight.org.au/Pages/default.aspx?gclid=CLaRwbmEhKcCFQPgbgodRBW1eQ

The Sydney Neuro-oncology Group www.snog.org.au/

The Telethon Kids Institute (WA) http://telethonkids.org.au/

The Tony Lucas Research Grant http://tonylucasresearchgrant.com/our-story/

The Warwick Cancer Foundation - http://twcf.org.au/

THANKS FROM THE BTAA

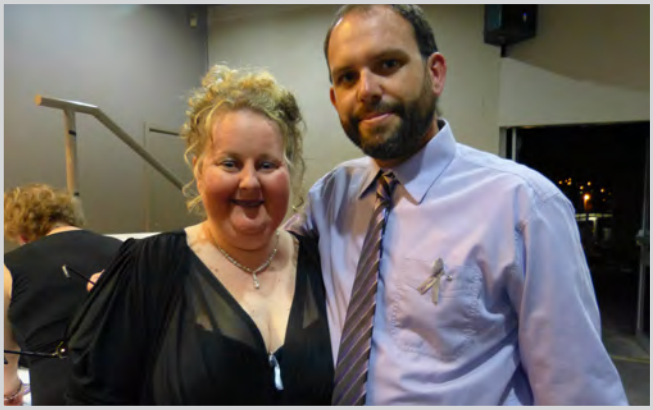
In addition to all those mentioned above, thanks to all who donated to BTAA via our bank account, the Everyday Hero Channel, or any other way including holding a Wear a Hat for a Day for BTAA. Thanks for ongoing support from:

Colin McCulloch and **Bartercard**; **Emma Warwick**; **Debbie Pollard**; **Anita Berghout** and the Rotary Club of Newcastle Enterprise and Rotary Club of the Lower Blue Mountains; **Phil Greenwood** and the **John James Foundation**; **Michael and Tracy Scott** and the family and friends of the late **Nicola Scott**; **Kate and Richard Vines** and **Rare Cancers** and **Rare Voices**; Ren Pederson and the **Cure Starts Now**; the team at the **Cure Brain Cancer Foundation**; **Sarah Mamalai** and **Amanda Fintan** and the team behind **Brainstorm for a Cure**; **Paul Bide; Mel** and **Peter Johnson** and the team behind **Mel Goes Gray in May; Mel Tempest** and **Ballarat Body and Soul**. Particular thanks to those who made donations in memory of the late **Judith Kuhnel,** the late **Pedro Cafe** and the late **Peter Knight.**

Special thanks to Senators **Catryna Bilyk** and **Scott Ryan** who co-convene the Parliamentary Brain Tumour Awareness Group; and to Senator **Claire Moore** who is a BTAA member and advocate for palliative care and carer's issues in particular; and Senator **Seselja** who supported **Dainere Anthoney** and continues to support her family's Rainbow Fund.

Our special thanks to the late **Erin Griffin** and her family for amazing advocacy and awareness raising.

Very special thanks to Matt's grandmother **Joan Pitt** who crochets little treasure bags to include in our paediatric packs and information kits. And finally thanks again to **Andrew Simpson** whose regular donations support the call service for our 1800 Freecall service.



Mel and Peter Johnson at 'Mel Goes Gray in May for BTAA'

Joan Pitt and her treasure bags.

KEY CONTACTS

BTAA Freecall
(From landlines) number
1800 857 221.
enquiries@btaa.org.au
treasurer@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.

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

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

Brain Foundation
www.brainfoundation.org.au
This group has useful information on its website for phone contacts for most States and advice about meetings.

Rare Cancers
www.rarecancers.org.au
contact@rarecancers.org.au

State/Territory Support Services and Groups
Visit www.btaa.org.au/support_groups.html

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Zac

Renee, Sarah, Yvonne and Charlie

Sarah Mamalai