Cancer Council Queensland

Brain Tumour Support Service

Edition 4, 2013

Dear Friends,

Welcome to the fourth edition of the newsletter for the year.

Anne M. Miller, *Volunteer Editor, Brain Tumour Support Service Newsletter.*

Welcome to the last edition of this newsletter for 2013. Yet another year has almost flown by - I know I say that every year, but I really don't know where it has gone to!

Andrew has written a beautiful story about his battle with a malignant oligodendroglioma. Thank you Andrew for being so honest and telling us how you were really feeling. Andrew says this experience has taught him to value every moment and how this has strengthened the relationship between him and his wife.

Next we have an article on the study of nutrition and dietetics which deals with the science of food and nutrition and their role in human health and disease. A most interesting and informative article.

Returning to work after treatment for a brain tumour deals with Fair Work information such as maximum hours of work, long service leave, public holidays, discrimination and unfair dismissal and plus so many other questions you may need to ask. There are also plenty of details for various agencies that may be able to assist you.

BrainChild writes for us again with an article about their inaugural Family Camp, held in May this year. The camp sounds like it was a fantastic weekend for everyone involved, providing much needed support to parents and their children.

At the time of going to print, Janine Rhodes, Coordinator of the Brain Tumour Support Service was hard at work putting together the program for the Patient Forum on November 2, 2013. Special thanks go to Gavin, Andrew and Bill for assisting Janine with topic ideas for the forum, as well as to Dr Tamara Ownsworth, Dr Po-Ling Inglis and Ms Vivien Biggs for their feedback and suggestions. In the first edition for 2014 we'll have an update on the day's proceedings.

We also hear from both the Brisbane and Townsville Coordinators of the Brain Tumour Support Service with information about what is going on in their respective regions.

Then of course we have all the usual resources and support services for you to contact if needed.

Till next time keep well and keep smiling,

Anne.

Thoughts for the month:

"Better by far that you should forget and smile, than you should remember and be sad." ~ Christina Rossetti.

"Memories of our lives, of our works and our deeds will continue in others." ~ Rosa Parks.

Index

About the Brain Tumour Support Service

Information, support and referral for people who have a brain tumour, their family and friends.

What the service provides:

- Information about benign and malignant brain tumours and treatment.
- Information about support agencies, rehabilitation services and CCQ's Practical Support Program.
- Regular meetings in Brisbane and Townsville that provide an opportunity to meet other group members and hear professionals discuss topics of interest.
- Regular newsletters for information and support.

For more information visit Cancer Council Queensland's website at www.cancerqld.org.au

Email: helpline@cancerqld.org.au
or call our Helpline on 13 11 20

Donate now

We use your donations to help fund our research and support services for cancer patients. Thank you for your generosity.

Your tax deductible donation will contribute to vital cancer research and clinical trials, support services for patients, their families and carers, and information and public education campaigns.

You can call our Donor Hotline on 1300 66 39 36, Monday to Friday from 8.30am to 5pm to make a one-off donation or to find out about the different donor programs that we offer.

My Story – Andrew

My name is Andrew Landers and my journey started on the 12th of June, 2011. I was out and about with my wife Katherine and daughter Tahnee - just like any other regular weekend - buying a few items for our new home which we had just moved into 10 days earlier.

We arrived at our local shopping centre and while going up the travelator, I suddenly felt very strange and dizzy. I remember trying to call out and reach my wife's arm but I could barely move a muscle (out of fear of losing my balance) or manage anything more than a murmur/slur. I was terrified I was having a stroke or something. Then I had my first seizure! I can still recall the look of sheer terror on my wife's face and that of our daughter Tahnee. I'd been a full-time dad for nearly seven years, a part-time sheet-metal engineer and, up until then, had always been Tahnee's "rock". Having never had anything go wrong with me in public before, I felt my privacy had been stripped bare and I had suddenly become a "display" that just had to be seen - I was even vomited on from a bystander!

From the shopping centre, I was taken to the hospital to have a CT scan and while waiting for the scan, I had an even bigger seizure and was rushed into CT immediately. After the scan, doctors told me I had a mass in the left frontal lobe and based on the shape and size it was likely to be a brain tumour, however I still needed an MRI for more clarity and detail. Four days later I had a surgical resection/debulk.

The surgery and second MRI helped determine I had a malignant oligodendroglioma. We were pulled into a small room by a surgical registrar and a nurse and told quite bluntly about what I had, what they did surgically, that it was still there and that they were waiting on results to see if I had any of the genetic co-deletions.

To be honest, at this time I had no real idea of what was really going on, due to the various medications I'd been given and the ongoing massive headache. All I remember is being told that I would need to undertake chemotherapy, radiation or both. I thought to myself "OMG, my mother tried chemo, I'm not old enough to have cancer, this is really scary". The only thing that really stuck with me throughout this time was being told by hospital staff "if you were to get a brain tumour, this is the one to get".

I was still very confused when the ward staff came to inform us that I was going to be discharged. We still hadn't seen anyone from social work or oncology and were advised someone from the oncology department would be "in touch" with us and that we should keep an eye out for a letter in the mail.

I remember coming home and feeling absolutely terrified - what if I have a seizure? What if I have one while I am alone? How will I ever cope with this horrible diagnosis? I also had to face the huge impact this was going to have on our everyday life. I was no longer allowed to drive which was a huge loss not only for me personally, but I wasn't sure how I was going to get our daughter to and from school or even how I would get the groceries. I felt like I lost my independence and it took me a very long time to come to terms with this. Thankfully I now have a restricted medical licence.

I first saw the radiation oncologist and I was told there was no known benefit to starting radiation earlier or later, they would just wait until things progressed. I didn't start my chemo (PCV) until late August...and let's just say chemo didn't like me very much. It made me so tired that I could barely get out of bed and the vomiting seemed uncontrollable. We had to accept that a violently ill ritual would begin about 6 hours after I had taken the tablets - you could set your watch by it – and then I'd vomit for about every 20 minutes or so for at least 5-6 hours. This meant that we had to modify when I took my anti-seizure drugs so they could get into

My Story – Andrew continued

my system and be effective before I got sick and also make sure I didn't take the chemo tablets until early evening so that being sick wouldn't interfere with our daughter trying to get to sleep. The vincristine started on day 14, as well as the procarbazine tablets and then vincristine again at day 28. By round 3, I was hospitalised for my first dose of lomustine as the side effects were so severe. By the time we had gotten to our fourth cycle, the side effects of vincristine were so bad it meant we had to cancel it due to the extreme pain in my lower legs and feet – I didn't just get "pins and needles", I got what I like to call "knives and forks". By the fifth cycle I was also reacting badly to the procarbazine, so this had to be cancelled. By the time I got to round 6, I was only on one out of the three drugs that I was meant to have. I felt so anxious about not being able to take all the drugs I was prescribed – I was wondering whether my chemo was going to be as effective as it could be had I been able to stay on all the medication or the entire duration.

My oncology team have been, and still are, very helpful, open and honest with me. I am extremely grateful to them as I have literally trusted them with my life. This has probably been the single area of care that I have had no real problems with, as trust is extremely important to me.

At the moment, I'm back to three monthly MRIs. Surgery has left me with some minor speech issues, which are often brought on by stress. My short term memory has never been the same and sometimes it feels as if it is non-existent. My right hand motor coordination is better than expected (for me and the medical team). The most challenging thing about living with a tumour is understanding that the tumour is not my entire life. I am still a person underneath. I am more than just a disease.

The reaction we've had from people about my brain tumour has varied - from being handled like I am so delicate that bubble wrap couldn't protect me, to absolute denial and unwillingness to accept that the tumour even exists. I know my wife tries to shield me from most of the negativity but I still see some of it and am shocked at the lack of compassion people have in posting various things on social media sites (e.g. Facebook etc). It seemed at times that some people acted like the cancer was contagious – keeping their distance from us or keeping their kids from playing with my daughter. Maybe they were scared I would have a seizure in front of them or their kids - I don't really know, but what I do know is that their actions really had a negative impact on my family and I.

On the other hand, Katherine and I have had several people surprise us with how much they truly care for us and what we are going through. Possibly the only real benefit of having a tumour is getting to know who your true friends are and who you can rely upon in an emergency or in difficult situations.

I don't want to offer anyone advice about what they should or shouldn't do. My circumstances have shown me that advice can often be unwanted and possibly irrelevant - everybody's journey is different and everyone takes different timeframes to come to terms with what they are going through.

What I do know is that this journey has taught me to value each and every moment and I am mentally stronger than I ever thought I could be. What I've also realised is just how much love and strength there is in the relationship between my wife and I – there's no way I would have been able to go through this without her.

Would you like to share your story with us?

Readers of our newsletter like to hear the personal stories of how others have coped with the diagnosis of a brain tumour.

If you would like to find out more about sharing your story with our readers, please contact:

Brain Tumour Support Service
Email: janinerhodes@cancerqld.org.au
Phone: 07 3634 5307

How can they help? Dietitians/nutritionists

By Bridget Kehoe
Public Health Coordinator (Nutrition and Physical Activity), Cancer Council Queensland.

Nutritionists and dietitians are health professionals who work to promote the overall health and wellbeing of individuals and communities by promoting healthy eating and the prevention and treatment of diet related disease.

The study of nutrition and dietetics deals with the science of food and nutrients and their role in human health and disease. Nutritionists work with the wider population to influence dietary patterns and behaviours as well as the wider food supply, while dietitians provide individual dietary advice and medical nutrition therapy.

Nutritionists may work in a range of settings including public health and community nutrition, indigenous nutrition and health, consumer and public health, and promotion of nutrition through the media as journalists and editors. Dietitians may work in these settings as well as in hospitals, nursing homes, community health centres and private practice.

Accredited Practising Dietitians (APDs) are regulated dietary professionals who are tertiary qualified in the area of nutrition and dietetics and are trained to asses an individual's diet in order to help treat a wide range of chronic diseases. In order to hold an APD credential a dietitian must have graduated from a Dietitians Association of Australia (DAA) accredited course, undertake ongoing training and education and comply with DAA's guidelines for best practice as well as DAA Professional Standards.

In Australia the use of the term Nutritionist has not been well regulated but the DAA and Nutrition Society of Australia (NSA) are working to establish accreditation for Nutritionists who are tertiary qualified and have the expertise to provide a range of nutrition services. Accredited Nutritionists (ANs) or Registered Nutritionists (RNutr.) must have graduated from a Bachelor or postgraduate degree in the area of nutrition science and have professional experience. They must comply with DAA or NSA guidelines and professional standards and commit to continuing professional development.

A brain tumour can impact on a person's ability to eat as they normally would, whether this be due to difficulties in eating or chewing (for example if you have a loss of coordination), or as a result of side effects of chemotherapy or radiation. A Dietitian can work with you to select appropriate foods to maintain weight and nutrition during treatment, deal with side effects such as nausea and vomiting or work with modified foods textures if you are having trouble eating.

After treatment many people decide to live a more healthy life and working with a dietitian or nutritionist can help you to achieve this. A dietitian can help to create a diet tailored to your individual needs while a nutritionist may work with groups of people to promote population health messages.

If you are admitted to the hospital because of your brain tumour you can ask to see a dietitian during your stay. If you are not currently attending hospital appointments you can see a dietitian in the community by seeing a private practitioner. You can do this with or without a referral from your GP; however it may be useful for the dietitian to know any relevant medical history. You may also be eligible for a Medicare rebate towards the cost of seeing a dietitian depending on your circumstances. Your GP can give you more information about your eligibility. Many private health funds provide rebates for visits to private APDs. You can find APDs in your area by contacting the DAA or looking on their website at www.daa.asn.au. Nutritionists can usually be accessed through non-government organisations, local hospital and health services or community organisations.

Returning to Work After Treatment of a Brain Tumour

A brain tumour diagnosis has a signficant impact on many aspects of a person's life, including their participation in employment.

In July 2013, CCQ's Cherie Everett, Executive Manager, Human Resources and Lisa Oughton, Human Resources Advisor presented at a Brain Tumour Support Service Information Session on returning to work after the treatment of a brain tumour. Cherie and Lisa outlined the basic entitlements under the National Employment Standards and Commonwealth and State disability and discrimination laws that may be relevant for people affected by a brain tumour and are returning to work.

The National Employment Standards are 10 minimum conditions for employees that came into effect on 1 January 2010. Together with the national minimum wage, they are a minimum safety net for employees. The 10 Entitlements under the NES include:

1. Fair Work Information Statement - employers have to give the Fair Work Information Statement to all new employees.
2. Maximum weekly hours of work - 38 hours per week, plus reasonable additional hours.
3. Requests for flexible working arrangements - parents and carers can ask for a change in working arrangements to care for young children under school age or children under 18 with a disability.
4. Parental leave and related entitlements - up to 12 months unpaid leave, the right to ask for an extra 12 months unpaid leave and other types of maternity, paternity and adoption leave.
5. Annual leave - 4 weeks paid leave per year, plus an extra week for some shift workers.
6. Personal/carer's leave and compassionate leave - 10 days paid personal (sick)/carer's leave, 2 days unpaid carer's leave and 2 days compassionate leave (unpaid for casuals) as needed.
7. Community service leave - up to 10 days paid leave for jury service (after 10 days is unpaid) and unpaid leave for voluntary emergency work.
8. Long service leave - entitlements are carried over from pre-modern awards or from state legislation. For details see the Long Service Leave and the National Employment Standards fact sheet available at www.fairwork.gov.au/resources/fact-sheets/national-employment-standards/pages/default.aspx
9. Public holidays - paid days off on public holidays unless it's reasonable to ask the employee to work.
10. Notice of termination and redundancy pay - up to 4 weeks' notice of termination (5 weeks if the employee is over 45 and has been in the job for at least 2 years) and up to 16 weeks redundancy pay.

Will I be able to work?

Apart from entitlements to leave, it is also important to consider the impact that your brain tumour diagnosis and treatment has had on you. Your ability to work will depend on the position of your tumour, the treatment and treatment effects, as well as how much support you have available (both at home and in the workplace), the type of work you do and your treating team's advice about returning to work.

If you want to return to work and require a flexible working arrangement, you and your employer should discuss if your role, hours and work site can be modified. Commonwealth and State anti-discrimination laws require employers to take reasonable steps to accommodate the effects of an employee's illness. Employees do have the right to request a flexible working arrangement and your employer needs to take reasonable steps to accommodate the effects of the brain tumour under Commonwealth and State disability discrimination laws. However, your employer isn't obliged to agree to all your requests and they can refuse requests for flexible working arrangements on reasonable business grounds.

Discrimination

Anyone who has had cancer is protected by Commonwealth law, the Disability Discrimination Act 1992, the Fair Work Act 2009 and the Anti-Discrimination Act 1991 (Qld). These laws prevent both direct and indirect discrimination against people with a disability in the workplace.

Direct discrimination is when an employee is treated unfairly or less favourably because of illness or disability. For example, you are refused a job because your partner is in hospital recovering from a

serious illness and your employer thinks you'll take too much time off work. Indirect discrimination is when a policy, rule or practice that seems fair actually disadvantages you because you have a disability. For example, your employer has a policy of not letting any staff work part-time. This policy impacts unfairly on you because you have young children and can't work full-time.

Unfair dismissal and discrimination

Unfair dismissal means that the termination of your employment is considered harsh, unjust or unreasonable. If an employee thinks they have been unfairly dismissed, they can lodge a complaint with Fair Work Australia. Unfair dismissal claims can be made to Fair Work Australia (FWA) and must be lodged within 21 days of the date of the dismissal. It is possible to have a claim heard after the 21 day notice period if the claimant can show exceptional reasons why the application was late. The fee associated with lodging a claim is $64.20.

What if I have an accident at work because of my brain tumour?

Queensland employees are protected by the workers' compensation system and legislation. If you've been injured at work, or because of your work, you may be eligible to claim benefits from WorkCover. WorkCover considers each case on the individual facts at the time. If an employee with any medical condition or disability has an accident at work and is injured, they should report this to the employer, obtain a WorkCover medical certificate from their doctor and lodge a claim with WorkCover within six months. For further information about employer and employee rights and obligations in relation to workplace injuries, please contact WorkCover Queensland and the Department of Employment and Industrial Relations www.deir.qld.gov.au/workplace/

Workplace Relations – Amendment of the Fair Work Act

On the 27th of June the Senate passed the Fair Work Amendment Bill 2013. Amongst other things, the amended Act contains new anti-bullying laws, introduces new family friendly measures, a right for the Fair Work Commission (FWC) to arbitrate adverse action claims and changes to the right of entry provisions.

The summary below is of the Bill as passed by the Senate.

Bullying commencement date 1 January 2014	**Who may apply**: A worker who '*reasonably*' believes he or she has been bullied at work may apply to the FWC. Importantly, this includes contractors and labour hire workers as well as employees. However, the person must be at work at a *'constitutionally-covered business*'. This excludes State public servants and employees of non-incorporated employers (amongst others). **Definition of bullying:** Bullying is defined to mean repeated unreasonable behaviour that creates a risk to health and safety, but does not include *'reasonable management action carried out in a reasonable manner'*. **Powers:** If FWC upholds the complaint, it may make any order it considers appropriate to prevent the bullying – but importantly, not payment of a *'pecuniary amount'*. It could include orders that behaviours stop, to provide training or review of the employer's bullying policy. FWC must also take into account other procedures available to the employee to resolve the dispute. **Other claims:** A worker will still be able to make other claims in relation to the alleged bullying – e.g. workplace health and safety, adverse action, unfair dismissal or discrimination.
Family Friendly Measures - commencement date not yet set, but by 27 December 2013	**Concurrent parental leave:** Both parents may take eight weeks unpaid concurrent parental leave (as opposed to three weeks). Importantly, this concurrent leave can be taken in up to four separate periods of two weeks or more. Particular employees may request a change in working arrangements (e.g. part time employment, changes in hours or work locations). Employees who can make the request include parents of school age children or under, carers, disabled employees, employees aged 55 and over and domestic violence victims. Employers may only refuse this request on reasonable grounds. A new set of criteria has been included for reasonableness that sets a 'high bar' – such as the arrangements being 'too costly for the employer' or there being 'no capacity' to change the working arrangements. Safe job: A pregnant employee is entitled to transfer to a safe job in the event of illness, risks or hazard. The employee's salary must be maintained or – if there is no safe job – they are entitled to paid leave.
Adverse Action - commencement date 1 January 2014	**Arbitration:** FWC can arbitrate by consent of all parties, instead of Court proceedings. **Appeals:** An appeal to the Full Bench of the FWC is available, but there are limits on appeals on questions of fact (only significant errors). **Costs:** FWC has power to award costs against parties and/or their representatives on the basis of unreasonable conduct (including where the representative encouraged commencement of proceedings without reasonable prospects of success).
Consultation Over Changes to Hours or Rosters - commencement date (in effect) 1 January 2014	**Award / EBA provisions:** Both modern awards and new enterprise agreements must include a term that requires the employer to consult employees about a change to their regular roster or ordinary hours of work.
Penalty Rates – commencement date 1 January 2014	*New modern award objective:* A new modern award objective will be included – the '*need*' to provide additional remuneration for working overtime, unsociably regular or unpredictable hours, weekends or public holidays or shifts. This raises interesting questions about annualised salary provisions in some awards.
Right of Entry – commencement date 1 January 2014	**Use of cafeterias:** If the employer and the union cannot agree on the location of union interviews or discussions, a union official may meet employees in a room used for meal or other breaks. **Frequency of right of entry:** FWC may deal with disputes about the frequency of entry to hold discussions, but it can only arbitrate if the frequency of entry would *'require an unreasonable diversion of the occupiers critical resources'*. **Accommodation and travel for remote areas:** The employer must provide accommodation and travel to the permit holder – subject to some constraints (but only if the employer is providing accommodation and/or travel to employees). The employer may charge a reasonable fee to cover its costs.

For further information and advice, contact:

FairWork Australia Commission (Queensland office)
Website: www.fwc.gov.au
Telephone: (07) 3000 0399
Email: brisbane@fwc.gov.au

Fair Work Australia Ombudsmen
Website: www.fairwork.gov.au
Phone: 13 13 94

WorkCover Qld
www.workcoverqld.com.au
Phone: 1300 362 128

Department of Employment and Industrial Relations
Phone: 1300 369 915
www.deir.qld.gov.au/workplace/

Anti-Discrimination Commission Queensland
www.adcq.qld.gov.au/

Other information:

"Cancer, Work and You. Information for employed people affected by cancer". This booklet is available from Helpline on 13 11 20 or online at www.cancercouncil.com.au/wp-content/uploads/2011/08/CAN3461_Cancer-work-and-you_final-low-res.pdf

The information in this article does not constitute legal advice. This article provides general information only about employee entitlements based on the provisions of the National Employment Scheme and Commonwealth and State disability and discrimination laws. If you require legal advice specific to your circumstances please seek independent legal advice. For further information you can also contact the organisations listed in this article.

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c·vivor

active cancer support

c-vivor is an activity-based peer support program which brings together people who have been affected by cancer to participate in a regular physical or wellness activity. The program aims to combine the benefits of physical activity with the well-known psychosocial benefits of peer support.

If you are interested in being a c-vivor group leader or member, please contact your regional CCQ Cancer Support Coordinator via our Helpline on 13 11 20.

The Brainchild Foundation Hosts its Inaugural Family Camp

In the last edition of Kids' Konnection we introduced the Brainchild Foundation and outlined our five key objectives. One of these vital areas is Support, whereby we help make the journey easier for each family. We offer financial support through specific financial assistance for families currently in treatment, information support through our brochures and website and family support through networking and camps. Family camps provide an opportunity for diagnosed children and their families to relax and meet other families and further extend their support network.

In this edition we are pleased to report on the success of our inaugural Family Camp. The Brainchild Foundation's Family Camp is for children diagnosed with brain or spinal cord tumours, who have completed their treatment. It is an opportunity for those children and their families to experience a well deserved break away in a relaxing and supportive environment, whilst providing enjoyable activities and the opportunity to share stories with other families who have had similar experiences.

Our inaugural camp was held at Kenilworth Homestead on the 8th and 9th of May this year. The camp was hosted by committee members David & Belinda Brunoli and Joy May. Nine families joined them for an action - packed weekend of fun which included pony rides, face painting, archery, raft-building and rock-climbing.

This provided a wonderful opportunity for the children to meet in a non-clinical environment, to forget about the rigours of treatment whilst appreciating their common bond and enjoy just being kids.

Parents did not miss out, they also enjoyed participating with their children in all the camp had to offer, with the added benefit of being able to network with other parents who have had similar experiences and who were keen to exchange stories, opinions and encouragement. Accommodation and meals were provided and the families were treated to a delicious BBQ dinner as they wound-down around the fire on Saturday night.

How Networking with Other Families can Help You

The experience of having a child diagnosed with a brain or spinal cord tumour is arguably one of the most feared experiences a parent could possibly imagine. The effects of such an event on the life of the child and their family are profound and on-going, and can significantly impact the social and psychological wellbeing of its members.

The treatment period is obviously a time filled with overwhelming new experiences for all involved. The whole family must come to terms with a myriad of terminology and explanations about what is happening to the child they love. Diagnosed children often need to

Fun and games at the BrainChild Foundation's Inaugural Family Camp, May 2013

endure lengthy stays away from home, as they live in areas remote from their treating hospital. This may sometimes involve entire families having to relocate, or alternatively families having to be separated during the treatment phase. As difficult as this period is, it is a busy time of active engagement with many health care professionals which maintains a focus for the whole family.

Completion of treatment is always a cause for celebration; that some degree of normalcy may return to the family unit. Although this is a much welcome milestone in a child's journey, the weeks and months that follow can often be a time when families become a little 'lost'. Parents in particular can feel somewhat depressed as they no longer require the intense support from their treating hospital as they did during their child's treatment, and there is always the concern in the back of every parent's mind that their child may succumb once again to their illness. Affected children may feel somewhat disillusioned by the long time required for their minds and bodies to recover from the effects of radiation and chemotherapy. And then there are siblings who simply may not understand why this all happened and why life is just not as it used to be.

Networking among families provides a beneficial source of support for all concerned. It allows an informal and relaxed opportunity for people to debrief, regroup and refocus. Attending a Family Camp following treatment is an ideal way to initiate this process. It provides a much needed boost for diagnosed children as they benefit from the social aspect of camping in an environment where they are understood by others of their own age. Interacting with similarly affected children can reduce a child's anxiety regarding their illness. The opportunity for parents to engage with other parents who have walked a similar road can also be a source of comfort as they can discuss their experiences, feelings and fears among those who truly understand.

If your child is currently having treatment or has completed their treatment and you would like to attend our next family camp, we would love to hear from you. Please visit our website http://www.BrainChild.org.au/contact or call 1300 272 462.

As we all know, none of our wonderful support initiatives would be possible without the generosity of our supporters who contribute to the Foundation during our ongoing fundraising activities.

If you would like to know how the Brainchild Foundation can help you during your child's journey please access our website at http://www.BrainChild.org.au/contact and navigate to *Support* on the *contact us* page.

brain child

...beating childhood brain tumours for better tomorrows...

Cancer Council Queensland and the Brain Tumour Support Service are pleased to support the BrainChild Foundation and welcome them as our authors for the "Kids Konnection" articles in the Brain Tumour Support Service newsletter. Thanks to BrainChild for working with us and sharing valuable information about services and supports for children affected by brain tumours, as well as their families.

What's been happening in Brisbane… from Janine Rhodes, Brain Tumour Support Service Coordinator

It's been a pretty busy time for me since I started at the Brisbane office in May this year. New to Cancer Council Queensland, I hit the ground running to keep up with the activities of the Brain Tumour Support Service (BTSS).

I've really enjoyed the learning curve, but the best part for me has been the opportunity to meet and speak with some wonderful people who have either been diagnosed with a brain tumour, or are supporting someone with a brain tumour – some of whom also volunteer their time for Cancer Council Queensland or other neuro-oncology organisations. The other inspiring part of this job has been working with dedicated neuro-oncology health professionals, both in the public and private sectors, who are always ready to donate their time and expertise to BTSS events.

The big event as we go to press is the Brain Tumour Consumer Forum on Saturday November 2, 2013. On the day we will hear from a patient and carer about their experiences of brain tumour, plus sessions from health professionals on research and treatment, identity changes after a brain tumour, information about practical and emotional support services and palliative care.

We hope to offer as many of the sessions as possible as audio recordings and/or provide copies of handouts on our website, so keep your eyes peeled for these on our website over the coming months.

Once the Consumer Forum is over, I'll head into planning for 2014, which will involve getting your feedback about how the Brain Tumour Support Service can better assist you in future. One of the key issues I'll be seeking your feedback about is whether you'd like to see a brain tumour support group started, and if so, how would that run. For example, would such a group be:

- Led by peers (i.e. someone who has been diagnosed with a brain tumour)?
- Led by a health professional?
- Held as a face-to-face meeting, online chat or be a video-conference?
- Inclusive of both carers and those diagnosed with a brain tumour? Or would separate groups be offered for carers and patients?
- Held during business hours, or after hours? On weekdays or weekends?

If you have any ideas or interest in attending or leading a support group, please contact me on janinerhodes@cancerqld.org.au or telephone 3634 5307. When contacting me, please remember that I work part-time three days a week, so there may be some delay in my response to you.

Take care,

Janine Rhodes
Coordinator, Brain Tumour Support Service

What's been happening in Townsville…from Matt Burr, Cancer Care Coordinator

As this is the first article I have submitted to the Brain Tumour Support Service Newsletter, I thought that I would take this opportunity to introduce myself.

My name is Matt Burr and I am the new Cancer Support Coordinator in the Townsville Cancer Council Queensland office, and part of my role is to assist with the Brain Tumour Support Service. Before I get into all of the upcoming programs and information sessions that we are running through the Townsville CCQ office, I thought that I would let you all know a little about my background.

I have been working in the community/not-for-profit sector for about 10 years now, since completing my studies in Community Welfare at James Cook University. Most recently I spent over four years working with CanTeen 'The Australian Organization for Young People Affected by Cancer,' both in their Newcastle and Townsville offices. During that time I was privileged enough to have spent time with some inspirational families going through some pretty difficult circumstances, but I found being able to help these families find a bit of joy during tough times, to be an extremely rewarding experience. I hope to be able to continue to successfully assist people who are dealing with cancer in my new role with Cancer Council Queensland.

The experience of cancer can be demanding, both for your body and your mind. Diagnosis and treatment may stir up a range of challenging thoughts and feelings both for the person and their loved ones. Learning new ways of managing difficulties can be useful for all of us, regardless of life stage or the situation we find ourselves in. To help with these thoughts and feelings, our resident psychologist Helen Stubbings runs a Living Mindfully course over an 8 week period. Each session lasts for about 2 hours with a limited number of participants. Sessions involve meditation practice and facilitated group discussion. The last course for 2013 recently started but we will be running more in 2014. These sessions are available for anybody who is or has been distressed by cancer (including support persons) at any stage after diagnosis. Helen is also available to provide support to people affected by cancer through our free Cancer Counselling Service.

Cancer Council Queensland also runs a c-vivor program. c-vivor is a community based active support program for people affected by cancer. We currently have two activities up and running in Townsville, our c-vivor beginner's yoga course is currently running for a second time, and we will have some art classes starting up in early November. Both of these groups will be run throughout 2014.

Whilst our Living Mindfully Sessions, Cancer Counseling Service and c-vivor programs are for anyone affected by any type of cancer, we also run support and information sessions for people affected by brain cancer in Townsville.

We aim to hold four sessions per year and topics presented by guest speakers have been interesting and varied. Our Townsville sessions allow for plenty of interaction and discussion time. We provide refreshments and the opportunity for questions or a chat following the presentations. The last session for this year will be held on Monday the 9th of December at 5.30pm at Cancer Council Queensland's Townsville office at 24 Warburton St, North Ward. The session will be facilitated by our resident psychologist Helen Stubbings and will be on the topic of 'Maintaining Wellbeing while Living with Uncertainty'. We have also already secured a speaker for the first session of next year, with Anna Thomasen, psychologist from the Townsville Hospital, coming to speak about 'Understanding Brain Cancer: coping with depression, anxiety and memory loss'. If you have any topics that you are interested in hearing about, or have suggestions about days or times that suit you for meetings, please don't hesitate to contact me.

If you have any questions about any of the programs I've mentioned today , or any questions at all about the Townsville Brain Tumour Support Service please contact Matt Burr, Cancer Support Coordinator on 07 4796 8408 or via email at matthewburr@cancerqld.org.au

Brain Tumour Information Sessions 2013

Brisbane

There are no more Brain Tumours Support Services Information Sessions scheduled for the Brisbane office in 2013, however we are in planning for the 2014 sessions

If there are any topics you would like us to include in our information sessions next year, please contact Janine Rhodes via email on janinerhodes@cancerqld.org.au or (07) 3634 5307.

Please note: Most sessions will be held at Cancer Council Queensland (553 Gregory Terrace, Fortitude Valley). Selected sessions may be held at designated hospital seminar rooms. Light refreshments and optional group discussions will be held after the 1hr presentation. For more information & to RSVP contact the Cancer Council Helpline on 13 11 20 or email helpline@cancerqld.org.au

Townsville

December

Date: Monday, December 9 – Christmas party
Time: 5.30 – 7.30pm
Topic: **Maintaining wellbeing while living with uncertainty**

Townsville will hold its last Brain Tumour Support Service Information in December 2013 and we will be begin planning for our 2014 sessions soon.

If there are any topics you would like us to cover in our information sessions next year, please contact Matthew Burr via email on matthewburr@cancerqld.org.au or on telephone (07) 4796 8408.

Please join us for the information sessions, which are held at Cancer Council Queensland in Townsville, 24 Warburton Street, North Ward. The sessions are followed by light refreshments with all invited to stay for an informal group discussion.

For more information & to RSVP contact Matthew Burr on (07) 4796 8408 or email matthewburr@cancerqld.org.au

What's happening in 2014? Dates for your calendar…

Mindfulness Meditation Group

"Living Mindfully" is the name of an 8 week mindfulness meditation group that is being offered to people who would like to learn new skills for managing difficult cancer related emotions. The group commenced in 2010 following increasing evidence that mindfulness meditation is an effective treatment approach for people coping with cancer.

The "Living Mindfully" programme is based on Mindfulness Based Cognitive Therapy (MBCT). MCBT is an integration of cognitive-behavioural therapy with an eastern meditation approach to increasing awareness and acceptance of difficult thoughts and feelings.

"Living Mindfully" groups are planned for Brisbane, Townsville, Rockhampton, Sunshine Coast and Gold Coast. The group meets for about two hours, once a week for 8 weeks and is conducted with a maximum of 12 participants by specially trained facilitators. Participants are expected to commit to regular daily meditation practice for the duration of the group, with graduates of the group supported to continue their practice when the group finishes. Anyone affected by cancer (including patients and carers) can attend at any time after diagnosis.

There is no fee for attending the group however there may be ways you could help us continue our work by obtaining Medicare or private health fund rebates or via a small donation.

To refer to the "Living Mindfully" group, please contact the Helpline on 13 11 20 for further information.

Listen to podcasts

You can find our brain tumour pod-casts at Cancer Council Queensland's website www.cancerqld.org.au. The podcasts listed here were audio-recorded at Information Sessions & Forums held in Brisbane.

Brain Tumour Information Sessions

Topic: **Using complementary and alternative therapies for brain tumours - how do you know what is safe? (Video)**
Presenter: Dr Christine Carrington, Senior Consultant Pharmacist, September 3, 2013

Topic: **Depression and anxiety after the diagnosis of a brain tumour**
Presenter: Kate MacMorran, Clinical Psychologist, CCQ - May 21, 2013

Topic: **Brain tumours in adolescents and young adults**
Presenter: Dr Sarah Olson, Neurosurgeon
Dr Melissa Jessop, Paediatric/AYA Oncologist – March 26, 2013

Topic: **Managing fatigue related to a brain tumour**
Presenters: Jodie Nixon, Occupational Therapist & Elizabeth Pinkham, Physiotherapist – October 30, 2012

Topic: **Managing changes in thinking, emotions, and behaviour following diagnosis of a brain tumour**
Presenters: Joanne Oram and Helen Tinson, Neuropsychologists – July 3, 2012

Topic: **When a parent has a brain tumour – how to talk to your kids**
Presenter: Assoc. Professor Jane Turner, Psychiatrist – May 29, 2012

Topic: **Clinical trials in brain tumours**
Presenter: Dr Zarnie Lwin, Medical Oncologist – November 1, 2011

Topic: **Low grade gliomas**
Presenter: Dr Lindy Jeffree, Neurosurgeon – September 13, 2011

Topic: **High grade gliomas – diagnosis, surgery and latest treatment**
Presenter: Dr Sarah Olson, Neurosurgeon – March 29, 2011

Brain Tumour Forums

Brain Tumour Clinical Education Day held at CCQ in Brisbane - May 3, 2013

Topic: **Strategies to improve care coordination for brain tumour patients and carers**
Presenter: Dr Kiew Soh

Topic: **End of life issues for patients and families**
Presenter: Dr Mark Deuble

Brain Cancer Action Week Forum 2012

Topic: **Radiation therapy for brain tumours**
Presenter: Dr Matthew Foote, Radiation Oncologist

Topic: **Living with a brain tumour – Adjusting to your prognosis**
Presenter: Associate Professor Jane Turner, Psychiatrist

The Brain Tumour Alliance Australia (BTAA) Forum held at CCQ in Brisbane – August 11, 2012

Topic: **A patient perspective**
Presenter: Ms Renee Hindson

Topic: **The views of a Neuropsychologist**
Presenter: Dr Gail Robinson, Neuropsychologist

Topic: **Current and promising therapies for adult brain tumours**
Presenter: Professor Susan Chang, Neuro-oncologist

Topic: **Living with a brain tumour: patient and caregiver needs**
Presenter: Professor Susan Chang, Neuro-oncologist

Making Connections

Talking to others who have also been affected by the diagnosis of a brain tumour can sometimes help. Depending on what suits your needs and what you're most comfortable with you can meet people over the telephone, online or face-to-face through a brain tumour support group. Some of these options are:

Cancer Connect (telephone)

Cancer Connect is a free and confidential service provided by the Cancer Council, which can put a person who has been diagnosed with a brain tumour, their partner, carer or family members in telephone contact with a support volunteer who has had a similar diagnosis. People are matched based on similar circumstances such as type of tumour, age and treatment.

Volunteers are trained to provide practical information and emotional support, complementing the care provided by the patient's health care team. They do not give medical advice or provide professional counselling.

For more information contact the Cancer Council Helpline on 13 11 20.

Brain Tumour Patients Telephone Support Group (telephone)

Cancer Council New South Wales' Brain Tumour Telephone Support Group provides the opportunity for you to talk with other people living with a brain tumour. Group members range from those who are newly diagnosed, to those who have been living with a brain tumour for some time. Being telephone-based, you can join the group from anywhere in Australia. All you need is an hour, a telephone and a quiet, private space. Participation is free and confidential. Two trained co-facilitators co-ordinate the groups, which run for one hour.

Any adult who has been diagnosed with either a benign or malignant brain tumour can join.

Brain Tumour patients telephone support group meetings are held on the FIRST and THIRD Monday of each month.

For more information or to join: Free call 1300 755 632 Monday - Friday 9am - 5pm or email: tsg@nswcc.org.au

Cancer Connections (online)

You can talk online with other people about your experience with a brain tumour diagnosis. Cancer Connections is an online community set up by Cancer Council New South Wales that links people with cancer, their friends and families in all states. Registration is free and your contact details will remain confidential. The site is supervised and the administrator is available on-line during business hours. For more information visit website: www.cancerconnections.com.au

CCQ's Brain Tumour Information Sessions (face-to-face)

You can meet people informally at our Brain Tumour Information Sessions, which are held five times a year for patients, carers and their families in Brisbane and Townsville. A presentation from a health professional on a brain tumour related topic is followed by a relaxed morning tea where you can meet others.

For more information call the Cancer Council Helpline on 13 11 20.

United Brain Tumour Support – Gold Coast support group (telephone or face-to-face)

United Brain Tumour Support is an independent support group based on the Gold Coast. The group meets in a relaxed atmosphere and is for all brain tumour patients and their families. "We connect people together through talking, listening and understanding their day to day issues with having a brain tumour and how it affects them and their families. If you are interested in joining our group, please do not hesitate to contact us".

The group meets at Tugun Surf Life Saving Club, 29 O'Connor Street, Tugun at 10:30am on the THIRD Wednesday of each month.

For more information contact Peter on 0422 784 885 or visit their website: www.braintumourhelp.com.au

Services of Cancer Council Queensland

Cancer Council Queensland services are provided free.
Services may vary throughout Queensland.

For further information about services in your local area please contact:

Cancer Council Helpline 13 11 20 Monday to Friday, 8am to 6pm.
helpline@cancerqld.org.au or www.cancerqld.org.au

Brain Tumour Support Service

Provides support for people affected by brain tumours, their family and friends through regular newsletters and meetings that provide opportunities to meet other group members and hear health professionals discuss topics of interest. Meetings are held in Brisbane and Townsville.

Cancer Counselling Service

A free and confidential telephone and face-to-face counselling service to help people with cancer and those close to them. The Cancer Counselling Service aims to help by providing emotional support and strategies to work through cancer-related challenges. People can be referred to the service by calling Cancer Council Helpline on 13 11 20.

Cancer Council Helpline 13 11 20

Provides information, support and referral to support services for people affected by cancer and brain tumours. The trained staff can provide information about the various types of brain tumours and their treatments, and can send booklets, information sheets and other resources.

Look Good… Feel Better Program

Workshops conducted by trained beauty consultants, dedicated to teaching people beauty techniques to help restore their appearance and self-image during and after treatment.

Practical Support Program of Cancer Council Queensland

- Accommodation facilities for country patients.
- Assistance with transport costs.
- Wig and Turban Service.

Cancer Connect

A free confidential service that puts you in touch with trained volunteers who have had a brain tumour diagnosis.

Cancer Council
Queensland

For further information about these and other services provided by Cancer Council Queensland please call our Helpline on 13 11 20.

Thinking about starting your own brain tumour or cancer support group? Call Cancer Council Queensland to find out how we can support you.

Support services for people affected by brain tumours

Acquired Brain Injury Outreach Service (ABIOS)

ABIOS is a specialist community-based rehabilitation service for people with an acquired brain injury located in the Princess Alexandra Hospital, Brisbane.

☎ (07) 3406 2311
💻 abios@health.qld.gov.au
💻 www.health.qld.gov.au/abios

The Australian Pituitary Foundation Ltd

The Australian Pituitary Foundation Ltd was founded in Sydney in 1994 by pituitary patients and family members, with the endorsement of Australian endocrinologists, neurosurgeons, radiation therapists and endocrine nurses, who saw the need to support people who have rare conditions of the pituitary gland. After five years the APF developed into a company with benevolent status, limited by guarantee.

The Mission of the Australian Pituitary Foundation is to provide support to those who have experienced pituitary gland conditions. APF promote awareness and disseminate information among the medical community, public, pituitary patients and their families.

☎ 1300 331 807 (National)
1300 307 886 (Queensland)
Sue Kozij, Director,
Australian Pituitary Foundation Ltd
💻 qld@pituitary.asn.au

Beyondblue: the national depression initiative

Beyondblue works to raises awareness of mental health issues and produces information on depression, anxiety and related disorders.

☎ 1300 22 46 36
💻 www.beyondblue.org.au

Carers Queensland

Carers Queensland is a not-for-profit organisation dedicated to supporting carers through the provision of information and support including regional carer services officers and counselling.

☎ (07) 3900 8100 or toll free 1800 242 636.
💻 www.qld.carersaustralia.com.au

CanTeen Counselling Service

A free service for young people aged 12-25 who have a parent with cancer or a parent who has died from cancer. The service offers both one-on-one and group counselling options. Counselling can be carried out face-to-face, over the phone or online.

☎ 1800 226 833
💻 support@canteen.org.au

Disability Information and Awareness Line (DIAL)

DIAL is a free, state-wide information and resource service provided by Disability Services Queensland.

☎ 1800 177 120
💻 dial@disability.qld.gov.au
💻 www.disability.qld.gov.au

Australian Disability Parking Scheme

Disability parking permits for eligible applicants whose ability to walk is severely restricted by a medical condition or disability.

☎ 13 74 68
💻 www.qld.gov.ua/disability/out-and-about/parking-permits/

Domiciliary Services

Provide a range of home services for example nursing, physiotherapy, occupational and speech therapy, as well as equipment, respite and palliative care. Examples include Blue Care, Ozcare and St Lukes Nursing Service.

☎ For contact details of the services nearest to you, call the Cancer Council Helpline on 13 11 20
or check the White Pages

Epilepsy Queensland Inc.

Information and support for people with epilepsy and their family. Books and videos on epilepsy for children, teenagers and adults.

☎ 1300 852 853
💻 epilepsy@epilepsyqueensland.com.au
💻 www.epilepsyqueensland.com.au

Hospitals

Services may vary between hospitals, and may include specialists, nursing staff, social workers, welfare officers, psychologists, chaplains, occupational therapists, speech therapists and physiotherapists.

☎ Enquire at your treating hospital for information about available services.

Lifeline

For urgent assistance and crisis support, be sure to contact Lifeline's 24-hour telephone counselling service.

☎ 13 11 14

Medicines Line

The Medicines Line gives confidential information on prescription, over the counter and complementary medicines for the cost of a local call. The Medicines Line is staffed by pharmacists.

☎ 1300 888 763

Rehability

Rehability is a private practice offering occupational therapy, social work and case management services. They offer a multidisciplinary team approach to clinical rehabilitation for acquired brain injury and neurological conditions, in both the home and clinic environment.

Address: 161 Richmond Road, Morningside, QLD 4170.

☎ (07) 3161 2471
💻 (07) 3161 2589
💻 www.rehabilityabiservices.com.au

Support services for people affected by brain tumours continued

Open Minds

Offers support to people with neurological changes and supports their integration back into the community.

☎ (07) 3896 4222

💻 www.openminds.org.au

Palliative Care Information Service

Toll free contact point for both the health community and the public to obtain information about palliative care and also to refer callers to the relevant service providers.

☎ 1800 772 273

💻 www.pcis.org.au

Queensland Acoustic Neuroma Association

Self-help groups for people affected by acoustic neuromas. Support includes pamphlets, information sheets, meetings, home and hospital visits and more.

☎ (07) 3397 3291

💻 www.qana.asn.au

Relaxation Centre of Queensland

Offer courses to assist with handling stress, communication, self-esteem, coping with change, relaxation, etc. Also offers books, tapes, videos, CDs, library services and numerous seminars by local, interstate and overseas speakers.

☎ (07) 3856 3733

💻 relaxationcentreqld.com.au

Self Help Queensland

Information about self-help groups available throughout Queensland.

☎ (07) 3344 6919

💻 info@selfhelpqld.org.au

💻 selfhelpqld.org.au

Synapse (Brain Injury Association of Queensland)

The Brain Injury Association of Qld is now known as Synapse, a non-profit organization, dedicated to improving the quality of life of people living with and affected by Acquired Brain Injury or people whose behaviour challenges our understanding. They provide support for carers though their carers support group.

Level 1 – 262 Montague Road, West End, Brisbane Q 4101

☎ (07) 3137 7400 or toll free 1800 673 074
💻 info@synapse.org.au
💻 www.synapse.org.au

Technical Aid for the Disabled Queensland (TADQ)

TADQ provides reliable, good quality refurbished computers at very affordable prices to people with disabilities.

☎ (07) 3216 1733

Taxi Subsidy Scheme, Queensland Transport

The taxi subsidy scheme subsidises taxi travel for eligible applicants up to half the cost of a taxi fare (limits apply).

☎ 13 23 80
💻 www.qld.gov.au/disability/out-and-about/taxi-subsidy/

Resources available through our Cancer Council Helpline

A variety of information booklets and brochures are available to assist people who are affected by brain tumours.

To receive a copy of any of these resources, or to have information from the internet printed and mailed out to you please contact the Cancer Council Helpline by phone 13 11 20 or emailing helpline@cancerqld.org.au

- **About Brain Tumours**
  by Cancer Council Queensland
- **Brain Tumour Support Service Newsletters**
  By Cancer Council Queensland
- **Understanding Chemotherapy**
  by Cancer Council Queensland
- **Understanding Radiation Therapy**
  by Cancer Council Queensland
- **Coping with Cancer**
  by Cancer Council Queensland
- **Understanding Nutrition**
  by Cancer Council Queensland
- **Understanding Hair Loss**
  by Cancer Council Queensland
- **Complementary and Alternative Therapies**
  by Cancer Council Queensland
- **Living Well After Cancer**
  By Cancer Council Australia
- **Caring for someone with cancer**
  By Cancer Council Australia
- **Navigating the Internet**
  by Cancer Council Queensland
- **Adult Gliomas (Astrocytomas and Oligodendroglionas): A guide for patients, their families and carers**
  by Cancer Council Australia
- **Understanding Brain Cancer DVD: A guide for people facing a brain cancer diagnosis**
  by Cancer Council NSW & Cancer Australia
- **Brain Tumours and Driving: A guide for patients and carers**
  by Cancer Council New South Wales
- **Brain tumours, depression and anxiety disorders: factsheet 46**
  by Beyondblue & the Brain Tumour Alliance Australia (BTAA)

Resources available online

Brain Tumour specific resources are available online at:

Cancer Council Queensland
www.cancerqld.org.au (AUS)

Cancer Council NSW
www.cancercouncil.com.au (AUS)

Cancer Directory (Cancer Council Australia)
www.cancerdirectory.com.au (AUS)

Brainlink
www.brainlink.org.au (AUS)

Brain Foundation
www.brainfoundation.org.au (AUS)

Cancer Institute NSW
www.cancerinstitute.org.au (AUS)

Sydney Neuro-Oncology Group
www.snog.org.au (AUS)

Brain Tumour Foundation of Canada
www.braintumour.ca (CANADA)

National Cancer Institute
www.cancer.gov/cancerinformation (US)

Macmillan Cancer Support
www.macmillan.org.uk (UK)

Pediatric Brain Tumor Foundation
Resources about the diagnosis and treatment of children's brain tumours.
www.pbtfus.org

American Brain Tumour Association (ABTA)
www.abta.org (US)

British Neuro-Oncology Society
www.bnos.org.uk (UK)

Resources listed below are available in PDF format on the ABTA website www.abta.org

- *A Primer of Brain Tumors – A Patients Reference Manual*
- *About Ependymoma*
- *About Medulloblastoma*
- *About Pituitary Tumors*
- *Focusing on Treatment – Radiation Therapy*
- *Focusing on Treatment – Steroids*
- *Focusing on Treatment – Sterotactic Radiosurgery*
- *Focusing on Treatment – Surgery*
- *Focusing on Tumors – Ependymoma*
- *Focusing on Tumors – Glioblastoma Multiforme and Anaplastic Astrocytoma*
- *Focusing on Tumors – Meningioma*
- *Focusing on Tumors – Metastatic Brain Tumors*
- *Focusing on Tumors – Oligodendroglioma and Oligoastrocytoma*
- *Focusing on Treatment – Chemotherapy*

Clinical trials:

Australian New Zealand Clinical Trials Registry
www.anzctr.org.au

National Health and Medical Research Council Clinical Trials Centre
www.ctc.usyd.edu.au

The Co-operative Trials Group for Neuro-Oncology
www.cogno.org.au

About brain tumour awareness

There are a number of organizations and not-for-profit groups that are actively working to raise awareness of brain tumours and brain cancer. Patient and/or health advocacy groups aim to support and promote the rights of patients and their carers in the health care system. Some advocacy groups consist of consumers only while others are collaborations between health professionals and consumers. Some of these groups are:

Brain Tumour Alliance Australia (BTAA)

BTAA is a national brain tumour advocacy group established in 2008 by a group of brain tumour patients and caregivers. BTAA seeks to represent the brain tumour community from the viewpoint of the patient, family and caregiver. They work closely with the International Brain Tumour Alliance (IBTA) in its promotion of their annual awareness week in November. They also provide a free copy of the American Brain Tumor Association (ABTA) resource *A Primer of Brain Tumors: Patient Reference Manual* on request.

Phone: 1800 857 221 (not to mobile)
Website: www.btaa.org.au

International Brain Tumour Alliance (IBTA)
Website: www.theibta.org

The Brainchild Foundation

This Brisbane based charity was established in 2010 with the aim of helping children affected by brain and spinal cord tumours, and their families. The foundation is made up of a community of medical professionals, parents and friends of children affected by tumours of the brain or spinal cord. It aims to raise awareness of the challenges faced by families dealing with these diseases, to raise funds for research and provide support to families.

Website: www.brainchild.org.au/

Brain Cancer Action

Brain Cancer Action is an initiative of Cancer Council NSW and the Cancer Institute NSW's Oncology Group Neuro-Oncology. They held an inaugural Brain Cancer Action Week in 2010 and collaborate with consumers in order to raise awareness around brain cancer and funds for brain tumour research. Their website has brain tumour specific information.

Website: www.braincanceraction.com.au

CanSpeak Queensland

CanSpeak Queensland is a state-based, community organisation which aims to provide a unified, independent voice for all Queenslanders affected by cancer.

By developing partnerships with cancer patients, survivors, family members and health professionals working in cancer care, CanSpeak Queensland seeks to provide a forum to share issues, experiences and ideas common to all cancer types.

The goal of CanSpeak Queensland is to promote a better quality of life for those affected by cancer.

The objectives of CanSpeak are to:

- Provide a voice for those affected by cancer in Queensland.
- Define the issues important to consumers and advocate for measures to address those issues.
- Seek greater consumer involvement in decision making at all levels in the health system to ensure policies and programs reflect consumer views.
- Develop partnerships to pursue improvements in areas of common interest or concern.
- Reduce the impact of cancer by promoting a better quality of life for those affected.
- Assist in the promotion, establishment and employment of cancer advocacy and support groups.

CanSpeak Queensland Inc.
PO Box 201, Spring Hill Qld 4004
Email: info@canspeakqld.org.au
Website: www.canspeakqld.org.au

Calendar 2014 – Annual Brain Tumour Awareness Events

March 26
Purple Day for Epilepsy

April 27 - May 3
Brain Cancer Action Week

November 7
BrainChild Awareness Day

Cancer Council
Queensland

Further information and support can be provided at
any Cancer Council Queensland office throughout Queensland
or phone the Cancer Council Helpline 13 11 20.

www.cancerqld.org.au

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