

Dear Friends,

Welcome to this second newsletter for 2014, which focusses on research. There is an article on clinical trials, which is how we find out if a new treatment is better than the way we are currently treating patients. Trials are run by many different organisations, and there are trials which take place in Brisbane, across Australia and internationally. Anyone who takes part in a trial is given detailed information about the trial and understands what they are being asked to do. They also agree to be in the trial freely and sign the consent form – this is most important. To find out more about clinical trials, speak with your treating medical team or access information via the websites listed at the end of the article on clinical trials.



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

In this edition we hear from Dianne, who was diagnosed with a glioblastoma (GBM) and her journey through treatment, the impact on her family and what she is doing now to support others diagnosed with a brain tumour. Best wishes for your fundraising efforts Dianne.

The Brain Tumour Support Service talks with Associate Professor Stephen Rose of the Australian e-Health Research Centre, CSIRO, about what led him to becoming interested in research in brain tumours. Prof Rose was studying at the University of Queensland when he realised that imaging plays such an important role in the diagnosis and treatment of patients with brain tumour.

Cancer Council Queensland's own Professor Joanne Aitken, Head of Research and Director, Cancer Registries, also writes for us about just how critical research is for cancer control. Thanks to Joanne for this brilliant overview of the different types of research.

BrainChild has written an excellent article for us once again on paediatric brain and spinal tumours. Brain and spinal tumours are the second most common types of cancer in childhood and the most common cause of cancer death in children. However, they are also the most underfunded cancers for research worldwide, with charitable organisations seeking to fill the financial gap to raise funds for research.

Then of course we have all the usual news and information about services, including some details of the Forgotten Cancer study from Cancer Council Victoria.

'Till next time, keep cool, keep smiling and happy reading.

Anne.

Thought for the day:

"Love recognises no barriers. It jumps hurdles, leaps fences, penetrates walls to arrive at its destination full of hope."

~ Maya Angelou.

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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 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 – Dianne

It was Friday afternoon October 2012 when I was meant to be working that I found myself in an emergency department. Initially my concern was regarding my feet and the difficulties I was experiencing when first waking in the morning and when getting up from a chair after sitting for extended periods of time. This then led to having transient episodes of weakness in my right hand, gradually increasing in frequency and length of time. I initially thought perhaps I had multiple sclerosis.

My writing began to get worse and I remember a few episodes of being a bit cloudy mentally. Because it was both feet but only one hand it seemed that I was not text book anything! Whilst in the emergency department my hand and mind were out of sync again. An MRI was requested, but as it was all booked up, a CT scan was done, just in case of a stroke or bleed. It actually was a department that I had previously worked in as a registered nurse, so it was very comforting to have familiar faces around me.

My children were 17 months and 5 years old at the time. My husband Graeme had reluctantly dropped me off at the hospital so he could go collect my mother on the other side of town to come and stay with the children. He didn't want me there on my own. Just as I returned from CT scan, Graeme arrived at my cubicle. The doctor came and we were told there was a tumour. At that time it seemed likely to be a meningioma near the parietal/frontal lobe. The doctor said that they are "usually benign and the better one to have". Graeme and I just looked at each other and we held hands - for us, the tumour had to come out and we would move on and get back to normal. Further diagnosis was needed via MRI and a neurologist. From here on in, medical business cards started to fill my wallet.



Dianne and Graeme renew their wedding vows for their 20th wedding anniversary, February 2014. Picture from left to right: Dianne, Halle, Graeme and Cooper.

The results from the craniotomy proved to be far from the easy plan that we had expected. I was diagnosed with a grade IV glioblastoma (GBM). Certainly not fair, undeserved and, as I read in most peoples description of cancer, life changing. It has changed me in many ways, emotionally, mentally and physically. The cognitive changes have rendered me totally and permanently disabled, unable to continue in my role as a registered nurse. Of course Dr Google became a friend or enemy depending on what you read. Average survival 12-14 months. Enemy!

I dealt with the surgery so well and remember sitting at the kitchen table feeling great and saying it was surreal about what lay ahead - the "Gold Standard" of surgery, radiotherapy and chemotherapy. I had some partial seizures so my driving was restricted for six months. Cooper started his first year at prep just as I was starting my high dose oral chemo. Luckily his school was within walking distance. Fortunately I grew up travelling on buses, so I could still get around. Initially I had a great network of drivers for my radiotherapy and such an outpouring of love in the initial "well time". But once you say the scan is

My Story – Dianne continued

clear, it seems like you are fixed – but the effects of the radiotherapy and chemo start to kick in and that’s when you hit troubled waters. I went through some dark times and certainly didn’t feel like Dianne at all. 2013 was a difficult year. We had a few people who formed a core group that were there for us and my sister-in-law Gayle was our biggest support. I attended most appointments on my own, but any appointment where results were given I always liked having Graeme there. A tough thing for me was seeing how little support Graeme had from his friends, but I have come to accept that people deal with things in different ways. Most people said call us if you need us. But that’s just not who we are, so we never really did.

The kids didn’t quite understand when we were a bit stressed or so tired. I really struggled with the mental fatigue, and noise overload with 2 young children vying for attention. Halle, my daughter, who was very active and opposed to day time sleeps, proved to be too difficult, so I relied on day care for her three days a week. She didn’t understand that mummy needed to rest and during chemo weeks I needed as much as 2 hours during the day. That’s when her daycare increased. I was a new parent to the school. I felt I had to bide my time with whom I could confide in as I didn’t want “sympathy friends” and I wanted Cooper to find his own friends. No one knew me so they didn’t realise I had developed expressive dysphasia (difficulty with some words) or that I was anxious talking to them. They didn’t know that me

being unsteady on my feet is not me being unfit. I wore hats all the time or scarves - my hair loss was towards the back so I could hide it a lot - so I don’t think anyone noticed. My kids were used to me wearing scarves and Graeme has super-short hair, so I joked the “fuzzy” thing in my head had to come out and when it did I would have a crazy hairstyle. One of the worst things was feeling judged by parents when asked where my daughter was and saying she was in day care when they knew I didn’t work. I do wish these new friends had known the “old me”.

My last chemo round was in September 2013, two weeks before my sons sixth birthday party. I threw him an amazing Star Wars party in case it was the last one I did - I wanted it to be fantastic. I remember Graeme not wanting me to go to the Ekka. I surprised the kids on the last day and despite being on chemo I took them to the Ekka in case it was our only time. Graeme was not impressed but the kids and I had a fabulous time. It was exhausting but I don’t regret it. I have found that my life is “now” - no regrets. I cried tears of happiness at the end of the year when Cooper finished school because I didn’t think I would be alive to see it. It was 14 months. I had made it past the average survival.

It has taken a few months to start to feel better in and about myself. Some things are improving and some things are here to stay (like the reduced dexterity in my right hand and difficulties writing). I have started doing some work with an exercise physiologist twice a week. My relationship with my daughter



is improving and I do some volunteer work for a charity called Mummy’s Wish.

On February 26th this year we celebrated our 20 year wedding anniversary. We took the kids to Sydney and had a simple service to renew our wedding vows. Hopefully it will explain, in years to come, our commitment to each other and them. When we got back from Sydney, my daughter told day care “we got married!”

I am now focusing my energy on an event called Footprints for Brain Cancer which is being supported by CCQ. It is a 4 km flat walk through my suburb of Ashgrove on Sunday 4th May from 8.30am to 11.30am. The aim of the walk is to raise awareness of brain cancer and to raise much needed funds for research. Registration is \$20 and is required by 1st May. There will be plenty of music, drinks, raffles, entertainment and fun. Hopefully lots of money will be raised. Please come along. For further details see www.footprintsforbraincancer.com. Alternatively you can pay the cost of registration (\$20) as a donation via www.icanforcancer.org.au (please leave a note that your donation is for your walk registration).

Meet a Researcher

Associate Professor Stephen Rose of the Australia e-Health Research Centre – CSIRO, Royal Brisbane and Women’s Hospital talks to the Brain Tumour Support Service about research.



Q: What led to you becoming a researcher?

A: During my postgraduate days, studying chemistry at the University of Queensland (UQ) in the mid to late 1980’s, I became aware of a new imaging technology called magnetic resonance imaging or “MRI” as it is now commonly called. Although in its infancy, I realised that this new exciting technology was the future for diagnostic imaging. Even in the early days, it was clear that MRI afforded improved images of the brain and other organs, more so than anything else available at that time (such as x-rays or CT) and was non-invasive. I was fortunate to obtain a postdoctoral research position at UQ, using the first research based clinical MRI scanner installed in Australia. So I caught the research bug some 20 years ago and have spent the last two decades developing and applying new MRI technology to improve diagnosis, better understand and monitor disease processes and provide new ways to measure the effectiveness of new therapies. Over the last five years I have been very excited about combining the anatomical information obtained using MRI with the metabolic information available using positron emission tomography (PET) imaging. In fact, I predict that this is where the future lies for diagnostic imaging for oncology.

Q: Why brain tumour research?

A: In general, my interest is in neuroimaging research targeting Alzheimer’s disease, stroke, cerebral palsy and neonatal brain development. However, I have a special interest in brain tumour research as I have a sense that the current diagnostic imaging may be improved by using a hybrid imaging approach that incorporates both MRI and PET in the one scan. In fact, the major providers of diagnostic imaging equipment have now made commercially available hybrid MRI/PET imaging scanners, where patients can receive anatomical (MRI) and metabolic (PET) imaging using the one scanner in a single imaging session. We are very fortunate to have the first such scanner being installed in Australia mid-year at the newly established Herston Imaging Research Facility (HIRF) located at the Royal Brisbane and Women’s Hospital (RBWH). On a more personal note, my first research grant that I was awarded as an independent researcher was for studying brain tumours, so the topic will always be of special interest to me.

Q: What brain tumour research are you currently involved in?

A: Brain tumour imaging research involves input from a dedicated team of scientists and clinicians. At the RBWH, we have a multi-skilled collaborative research team involving specialists in molecular biology (QIMR Berghofer Medical Research Institute), diagnostic imaging (Department of Medical Imaging and Special PET Services Queensland), neurosurgery and medical oncology (Cancer Care Services), advanced image analysis and processing (Australian e-Health Research Centre, CSIRO), bioengineering and nanotechnology (Australian Institute for Bioengineering and nanotechnology, UQ) and clinical pharmacology (School of Medicine, UQ). This team receives funding for primary brain tumour research from the National Health and Medical Research Council (two project grants totalling over \$1,000,000) and support from Cancer Council Queensland (two project grants totalling \$400,000). The projects cover a range of studies aimed at: using advanced MRI and PET imaging to improve treatment outcomes; investigating why currently available treatments may not work for some patients; further developing new imaging agents for gliomas using monoclonal antibodies that bind to cancer cells; and investigating whether these antibodies may assist in delivery of drugs directly to glioma cells.

Q: Why is research important to those diagnosed with a brain tumour?

A: Imaging plays a fundamental role in treatment planning for patients with brain tumours. The funding of our research program has enabled the development of an imaging platform that provides improved assessment of the location and size of the primary brain tumour. This is important, as many of these tumours are highly infiltrative, with current MRI scanning unable to robustly measure the exact tumour boundaries. To overcome this hurdle we have developed a PET imaging protocol using the radiotracer ¹⁸F-FDOPA to accurately delineate tumour margins. This allows improved planning for neurosurgical resection of the tumour and more precisely defined administration of radiotherapy. This PET imaging technology can also be used to assess very early treatment response. These examples highlight the impact imaging research can have on improving outcomes for patients with brain tumours.

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Why research is critical

By Professor Joanne Aitken
Head of Research and Director, Cancer Registries, Viertel Centre
for Research in Cancer Control, Cancer Council Queensland

Cancer Council Queensland has played a significant role in support of cancer research over the past 50 years. In 2013, Cancer Council Queensland spent \$14.2million on research in Queensland.

Our Viertel Centre for Research in Cancer Control (VCRCC) focusses on research projects that address ways to prevent cancer, diagnose cancer earlier, help patients achieve the best possible quality of life after a cancer diagnosis and support cancer patients and their families. Our research projects are targeted to areas of high need where results can be translated rapidly into community programs to improve the lives of people affected by cancer. The three main areas of VCRCC's research work are:

1. Epidemiology - understanding the patterns and trends in cancer occurrence in Queensland and the factors that impact on diagnosis, treatment, clinical outcomes and survival;
2. Psycho-oncology – understanding the psychological and social needs of cancer patients and their families, and evaluation of programs to reduce distress following a cancer diagnosis; and
3. Community Engagement – understanding the important role of communities in supporting cancer control efforts through public health education, fundraising and volunteering.

In addition to the important work of the VCRCC, Cancer Council Queensland also supports research undertaken by universities, research institutes and hospitals. Each

year approximately \$7 million is awarded to researchers within these organisations to undertake important scientific and clinical research with the provision of research project grants, research fellowships, and scholarships to support scientists starting out in their careers.

So why is so much effort and funding directed to research? The answer is quite simple. Without ongoing research, cancer outcomes will not continue to improve.

Research occurs at many different levels. Laboratory based research examines cellular mechanisms of tumour growth, genetic characteristics and environmental factors that impact on the growth and development of cancer. In the hospital setting, both public and private, doctors and health professionals conduct clinical trials to determine if new treatments or treatment combinations can improve outcomes for patients. Health professionals across all disciplines undertake research to improve clinical practice outcomes and services to support patients.

Cancer research, including basic science, clinical and public health research, makes up a large percentage of all medical research undertaken in Australia.

The major provider of medical research funding in Australia is the federal government through its National Health and Medical Research Council. Funding is also



available from other federal departments and state and territory governments. Grants are allocated on a competitive basis and usually for periods up to a maximum of 5 years.

Unfortunately as governments try to rationalise their spending, budgets are cut and research funding decreases, so additional sources of funding for research are vitally important. Charity and benevolent organisations, supported through donations and bequests, help to fill this void. With the generosity of the Queensland community, Cancer Council Queensland plays a major role in helping Queensland cancer researchers to continue their important work.

Examples of CCQ-funded research include:

- Prof Linda Richards from the Queensland Brain Institute was supported with a two year project grant to investigate the role of genetics in development of high-grade brain tumours (gliomas). Results from this research have identified the molecular pathway that could be targeted by treatments to control the growth of these aggressive tumours.
- Prof Bryan Day from the QIMR Berghofer Medical Research Institute is also focussing his research on treatments for high-grade gliomas which are known to be difficult to treat and have poor survival. Prof Day's

research in animal models is investigating whether a type of antibiotic that specifically targets stem cells may be effective in treating these tumours.

There are currently a wide range of research activities into brain tumours being conducted both in Australia and internationally. Many of these projects show exciting promise for the development of new and more effective treatments. Some of these examples include:

Tumour vaccines to stimulate the body's immune system to attack the brain tumour.

- Angiogenesis inhibitors that impair blood vessel growth in the tumour.
- Growth factor inhibitors that work against proteins that help tumours grow and divide.
- Hypoxic cell sensitisers that can increase oxygen content in tumours, making them more likely to be killed by radiation.
- Electric treatment fields that generate mild electric currents to the brain (currently approved to treat glioblastomas in the US).
- New imaging and surgery techniques to make brain tumour surgery much safer and more successful. Some new techniques include Functional Magnetic Resonance Imaging (fMRI), Magnetic Resonance Spectroscopic Imaging (MRSI) and fluorescence-guided surgery.
- Advances in application of external radiation therapy to allow doctors to deliver radiation more precisely to the tumour, sparing normal brain tissue.
- New ways of delivering chemotherapeutic drugs to the brain by carrying them in tiny droplets of fat (liposomes) or attaching them to molecules that are able to cross the blood-brain barrier. Another method called convection-enhanced delivery enables chemotherapy agents to be delivered directly to the site of the tumour via a tube inserted into the brain through a small hole in the skull.

There is only one way to achieve improvements in cancer diagnosis, treatment and survival for all and that is through medical research. In recent decades we have made significant improvements in cancer survival overall but we still have a long way to go. Eventually, we will be able to successfully treat all cancers but we need to continue funding medical research to ensure that we reach that goal as soon as possible.

Reference: American Cancer Society (www.cancer.org/cancer/braincnstumorsinadults/detailedguide/brain-and-spinal-cord-tumors-in-adults-new-research)

Kids Konnection BrainChild

Research and paediatric brain
and spinal cord tumours

Brain and spinal cord tumours are the second most common types of cancer in childhood and they are the most common cause of cancer death in children. They also remain one of the most underfunded cancers in terms of research by governments across the globe.

Because of this, charitable organisations seek to fill the financial gap, raising much needed funds to support vital research. Research may seek to increase understanding of certain tumours, provide better treatments or ultimately develop cures for the various brain and spinal cord cancers which approximately 200 Australian children will be diagnosed with each year.

In consideration of the fact that brain and spinal cord tumour research is sadly underfunded, the Brainchild Foundation has contributed to two research projects since our establishment in 2010. These projects have been undertaken at the Queensland Children's Medical Research Institute.

The first was a project aimed at understanding why some medulloblastoma tumours do not respond to treatment as expected, or recur after a period of remission. It is thought that this could be due to the presence of 'stem cell-like' tumour cells that are very resistant to treatment. These cells may have

special survival mechanisms activated within them that make them resistant. These mechanisms may include the ability to survive in an environment low in oxygen. This study aimed to further investigate these survival mechanisms and how they may be manipulated to make the tumour more responsive to treatment.

The second project will have far reaching and on-going benefits for present and future research. When a child undergoes surgery to remove a brain or spinal cord tumour, a sample of the tissue is sent to pathology to identify the tumour type. The remainder of the tumour may be collected and kept for the purpose of future research. Permission is obtained from parents of diagnosed children who are willing for the otherwise unwanted tumour tissue to be stored and used for this purpose. The tumour tissue is kept frozen and preserved indefinitely for future use and the samples are coded to maintain anonymity. This is a process referred to as 'tumour banking'. Tumour banking is vitally

important in enabling scientists to conduct research in relation to brain and spinal cord tumours. Through the co-operation of affected families today, we may see the eradication of brain and spinal cord tumours in years to come.

The Queensland Children's Medical Research Institute laboratory had built up a collection of 'banked' tumour specimens over a six year period from more than seventy Queensland children who had undergone brain tumour surgery. Banked tissue provides a valuable research resource for the study of brain tumour biology. With additional funding, it is now being shared with research teams around the country.

The collection includes glioma, medulloblastoma, primitive neuroectodermal tumour, meningioma and ependymoma tissues, as well as rare cancers such as atypical teratoid rhabdoid tumour and pineal and choroid plexus lesions. While the laboratory has funding to collect, store and curate such tissue, they are limited in the amount of time



they can spend collaborating with other researchers to ensure these samples are used to their maximum research potential.

With financial assistance from the Brainchild Foundation, the Queensland Children's Medical Research Institute are able to allow more specialised processing and culture of 'banked' brain tumour tissue to be done locally. This will extend the number of collaborative research studies that can be conducted using this valuable resource. It will also enable detailed clinical outcome data to be retrieved from patient records. This greatly increases the relevance of banked specimens and allows researchers to draw more powerful conclusions from studies. This will in turn lead to improved brain tumour diagnostics and treatments.

Update on current major fundraising projects

As we mentioned earlier, fundraising is vital to the continuation of life-saving research into brain and spinal cord tumours. The Brainchild Foundation has two major fundraising projects currently underway.

Firstly, the Brainchild Foundation is very excited to announce that BHP Billiton Cannington Mine have chosen us as their charity of choice for 2014. They have several fundraising events

planned for 2014, and all money raised by them during the year will be allocated to research. Included in their plans are an open day, golf day and silent auction. They will be selling specially branded uniforms embellished with the Brainchild Foundation logo, and they have even had an excavator at the mine decorated with the logo as well. Their campaign was launched in January when representatives of the Brainchild Committee visited the mine. Among the group were children who have received treatment for brain tumours, and it was a wonderful opportunity for the mine's management team to meet them and hear their stories. We are most grateful for the support of BHP Billiton Cannington Mine and look forward to granting these funds to worthwhile research projects in the field of childhood brain and spinal cord tumours.

Secondly, you may recall we introduced you to James 'Jimmy' Harrington in a previous edition of the Brain Tumour Support Service Newsletter. Jimmy is from Adelaide, South Australia, and on the 19th of May 2013, he set out on a journey of epic proportions – an 18,000 kilometre walk around Australia. The purpose of his walk is to raise money and awareness for childhood cancer. Jimmy's chosen charity



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.

is the Brainchild Foundation, and the money raised along Jimmy's remarkable journey will also allow us to make considerable contributions to research. Jimmy hopes to hand over a sizeable cheque at the completion of his journey in May 2014. He has already walked over 12,000 kilometres and is due to arrive in Sydney on 24th of March. He has currently raised in excess of \$110,000 for the Brainchild Foundation. We are so proud of what he and his tremendously supportive family have achieved and wish him well for the remainder of his journey. If you wish to follow Jimmy's Walk, you can go to his Face book page: <https://www.facebook.com/JimmysWalkforCancer>.



Clinical trials

Why clinical trials are important

Just because a treatment is new does not mean it is better. Some new treatments may even be harmful. Clinical trials are the main way of finding out if a new treatment is better than the current best treatment of cancers, including the treatment of brain tumours.

Clinical trials are important because only proper, rigorous scientific testing can enable researchers to discover whether or not a new treatment (such as a medicine, surgical technique or type of radiotherapy) is better than the best available standard treatment. If a treatment has not been tested properly in clinical trials, it remains unproven and can be controversial.

Clinical trials give patients the opportunity to receive new treatments and to make a contribution to the improvement in the care of future patients.

Recent advances in brain tumour treatments have been made after researchers analysed the results of large, well designed and well conducted clinical trials. These trials have led to new treatments for brain tumours, which are now approved by the Australian Therapeutic Goods Administration and paid for by the Pharmaceutical Benefits Scheme.

The purpose of different types of clinical trials

Clinical trials in patients are usually performed after years of scientific testing in the laboratory and in animals. Any treatment that seems to be effective must then be tested in its effective in people with the condition.

Clinical trials are conducted over time at different stages to collect different types of information about the new cancer treatment. There are four phases numbered one to four (I–IV).

Phase I trials

Phase I trials are the first studies in patients. They aim to find out how the treatment should be given, how often it should be given, and what dose is safe. Treatments used in Phase I trials rarely cause a tumour response.

Phase II trials

Phase II trials continue to test the safety and side effects of the new treatment, and also evaluate how effective it is in treating patients with a particular disease.

Phase III trials

Phase III trials test the new treatment by comparing it with an accepted standard treatment to find differences in effectiveness against the disease, safety and side effects.

These trials are randomised, which means patients are randomly selected to either get the new treatment or get the standard current treatment. Neither patients nor the doctors can choose which

group a person will be in. This way of designing a trial ensures that patients in each group are similar overall.

Phase III trials can also be 'blinded', which means they are designed so that patients and doctors do not know which treatment the patient is receiving. This method makes the results more reliable, because it helps prevent patients' and doctors' expectations affecting their experience of receiving the treatment or observing its effects. However, sometimes a trial may not be blinded when it is not possible to disguise treatments. Cancer trials are not usually blinded.

Sometimes there is no accepted standard treatment that the new treatment can be compared with. In this situation a groups of patients taking the new treatment is usually compared with a similar group receiving usual care, or with a group receiving placebo.

Phase III trials provide the most reliable type of evidence. They are usually required by health system authorities before a new treatment can become a standard part of care.

Phase IV trials

Phase IV trials are usually run after a new treatment has already been proved effective in earlier trials, and has been approved by government for use in patients. These trials collect more information about long-term safety or side effects. Patients do not have to pay for the treatment in a clinical trial, so Phase IV trials also provide a way for patients to receive the new treatment even if it is not yet widely available or is too expensive (for example, when it is not subsidised by the Australian Government through the Pharmaceutical Benefits Scheme).

Who conducts clinical trials?

In Australia, clinical trials in patients with brain tumours may be conducted by:

- **Pharmaceutical companies.** Pharmaceutical companies that develop new medicines must complete phase I, II and III trials before they are permitted to market their product. Many clinical trials of new treatments for brain tumours are sponsored by pharmaceutical companies. These trials usually have a sound scientific basis and are well designed and conducted. All doctors involved in designing and running the trial (investigators) must declare their relationship to pharmaceutical company and any fees they have received.
- Money received by a clinical trials unit does not go towards a doctor's salary. The money is used strictly for the conduct and management of the trial.
- **Cooperative groups.** Cooperative groups are groups of doctors and researchers who share a scientific interest in a specific disease. Cooperative oncology (cancer) groups in Australia with a special interest in brain tumours include the Trans Tasman Radiation Oncology Group (TROG) and the Cooperative Trials Group for Neuro-Oncology (COGNO). These groups are usually funded through grants from state or federal government. They may also receive funding or medicines with which to run clinical trials from pharmaceutical companies. Most clinical trials run by cooperative groups are initiated and designed by specialist doctors.

- **Individual institutions or consortia.** Sometimes a clinical trial is conducted at a few hospital units or a small group of hospitals. These are usually smaller trials such as phase I or phase II trials, studies of diagnostic tests such as scans, or studies of psychological and social issues affecting people with brain tumours.

Who approves clinical trials?

Before patients can be enrolled onto a clinical trial in Australia, the trial must be reviewed by other expert clinicians and researchers to ensure that it is scientifically well designed and will be able to answer the study question.

It must also be reviewed by at least one registered Human Research Ethics Committee to ensure that the trial protocol adheres to national guidelines as set out in the National Health and Medical Research Council's statement on ethical conduct in human research.¹

Who participates in brain tumour clinical trials?

A small proportion of people with brain tumours participate in clinical trials. In Victoria, about one in twenty (5%) patients with gliomas participate in a clinical trial during their illness, according to recent data from the Victorian Cancer Registry.

¹ National Health and Medical Research Council, Australian Research Council, Australian Vice-Chancellors' Committee. *National statement on ethical conduct in human research.* Canberra: NHMRC; 2007.

Ideally, all patients should have access to treatment in a centre where clinical trials are offered. However, geographical distances are a barrier to participation for patients in rural and remote communities. For extremely rare cancers, like anaplastic astrocytomas and oligodendrogliomas, it is unlikely that there would be enough patients in Australia alone to run trials, but groups like the Cooperative Trials Group for Neuro-Oncology (COGNO) sometimes participate in international trials.

Participating in a clinical trial

Understanding what the trial will involve and agreeing to participate

Doctors running a clinical trial are responsible to make sure that every person who participates:

- Is given detailed information about the clinical trial, both verbally and in writing, before they agree to be involved.
- Understands what they are being asked to do.
- Agrees to be in the trial of their own will.
- Signs a document to show they have given their consent to take part.

This can be difficult when a person has cognitive impairment (problems with memory, thinking, reasoning, understanding information, making decisions or judging their actions). However, the National Health and Medical Research Council's statement on ethical conduct in human research² states that

² National Health and Medical Research Council, Australian Research Council, Australian Vice-Chancellors' Committee. National statement on ethical conduct in human research. Canberra: NHMRC; 2007

people with cognitive impairment are entitled to participate in a clinical trial. That document provides guidance for their participation, and states that in some situations³ consent can be given by another person who has been given legal authority to make decisions for the patient.

In some circumstances, a doctor may legally enrol a patient in a clinical trial even though the patient is unable to give their consent, if the treatment they will receive in the trial is in the patient's best interests. Patients and their families or carers should discuss these issues with the doctor.

Occasionally, a patient who is able to think clearly and wishes to participate in a clinical trial may be unable to sign the required forms due to a physical disability caused by the tumour, such as weakness of their writing hand. In this situation, alternatives depend on legislation that applies in that state or territory, for example:

- Spoken consent to participate may be legally valid if it is witnessed by an independent third party.
- Another person who is authorised under Guardianship legislation may be able to sign the consent form on the patient's behalf.

What participation might involve

People participating in clinical trials may be asked to undergo extra tests or answer survey questions, and take part in follow-up tests some time after the treatment.

³ The law governing who can give consent differs between different Australian jurisdictions. In some states, such as Western Australia, a person nominated to make decisions for a patient cannot give consent for participation in clinical trials.

Participation in brain tumour clinical trials may involve being asked to:

- Complete questionnaires about quality of life, which are designed to measure how the tumour and the treatment is affecting the person's wellbeing.
- Undergo tests to measure cognitive functioning, which can help researchers understand whether the treatment can improve thinking ability.
- Undergo extra blood tests to help researchers understand more about how the treatment works, who the treatment may be most effective for, how much of the treatment reaches the bloodstream, or side effects of the treatment.
- Give permission for the original tumour specimen (taken by biopsy or during surgery) to be sent to another place for more testing. This testing might help researchers understand more about how the treatment works or which future patients may have the most benefits from treatment.
- Participate in long-term follow-up after the trial treatment stops, either in person or by phone. This allows researchers to understand the long term benefits or side effects of treatments.

For further information about clinical trials, speak with your treating health care team or contact:

- The Co-operative Trials Group for Neuro-Oncology
www.cogno.org.au
- Australian New Zealand Clinical Trials Registry
www.anzctr.org.au
- National Health and Medical Research Council Clinical Trials Centre
www.ctc.usyd.edu.au

Brain Tumour Research funded by Cancer Council Queensland

In 2014, Cancer Council Queensland has committed a total over \$7 million towards its external funding program. This funding goes towards supporting cancer research throughout the state in the form of project grants, fellowships, travel/study grants and scholarships.

In this issue, we heard from Associate Professor Stephen Rose about his current brain tumour research (page 5). Other recently awarded brain tumour research project grants include:

Researcher: Dr Bryan Day, Queensland Institute of Medical Research Berghofer Medical Research Institute.

Project name: "Understanding the function of salinomycin as a DNA damaging agent and its relevance as a potential therapeutic agent for the treatment of malignant brain tumours".

Project outline: High-grade glioma (HGG) is the most common malignant primary brain cancer. Each year about the same number of Australians die from HGG as die from melanoma (approximately 1000). Therapy is almost never curative - even with the current standard of care, the median survival is less than 15 months. Salinomycin is an ionophore antibiotic which has recently shown effectiveness against breast cancer stem cells. Our preliminary laboratory investigations show that salinomycin has anti-proliferative effects, induces cell death and may selectively target the tumour propagating or stem cells in HGG. Given the dismal situation faced by HGG sufferers finding agents which can eliminate these aggressive cancers is an urgent clinical challenge. We now propose to perform a detailed analysis of the ability of salinomycin to target the stem cell population and confirm that salinomycin is an effective therapy for treating brain cancer using animal models. Our findings suggest the agent alone has dual function in both inducing DNA damage and preventing DNA repair, thus representing a new class of radiomimetic drug, which may be effective in the treatment of HGG

Researcher: Association Professor Greig de Zubicaray, University of Queensland.

Project name: "A prospective study of language function following surgical resection of left hemisphere primary brain tumours".

Project outline: One third to one half of all patients with primary left hemisphere brain tumours present with language difficulties (aphasia), and for a similar number this will continue post-treatment. Aggressive multimodal treatment regimens involve surgical resection, chemotherapy and/or radiotherapy. This approach may improve baseline language function, leave it unchanged, worsen it, or introduce new deficits. Post-surgical aphasia is a strong predictor of survival rate, mood and quality-of-life (QoL). No published studies are available describing the incidence of post-operative aphasia in Australian patients. Few retrospective or prospective studies have examined the nature of chronic aphasic symptoms following brain tumour resection. None have systematically examined the anatomical-functional relationships responsible for post-operative aphasic symptoms using modern brain imaging techniques. We will provide the first comprehensive data concerning risk factors for post-surgical aphasia in Australian patients, in addition to important information about the brain lesions responsible for its various clinical presentations. This information will be used to generate recommendations for clinical practice and clinical trials.

Researcher: Associate Professor Jennifer Martin.

Project name: "Targeting existing therapies with innovative technology platforms to improve survival in brain cancer".

Project outline: Primary brain tumours are the most prevalent and aggressive malignant brain tumour with over 1,400 new cases of glioma in Australia/year. High grade glioma (HGG) pose a significant challenge in neuro-oncology because of their pervasive nature, propensity for recurrence and resistance to conventional therapies. Significant neurological deficits occur with current therapies and despite the recent advances in resection techniques and delivery of adjuvant therapies, the prognosis of HGG has a median survival of 12-18 months. Although several new drugs show potential promise for use in HGG, the translational period to the clinic is long, safety profile unknown and likely funding uncertain. Further, the molecular biology of this tumour is very heterogeneous and therefore difficult to design new targeted therapy for. Thus to have immediate impact on patient survival and to address the non-specific nature of this tumour we propose to explore the use of an old drug, sodium valproate as an effective, safe, low cost adjuvant and radio-sensitising therapy for HGG. We will use a novel imaging platform and molecular markers known to correlate with HGG progression as a surrogate method of drug effectiveness. This innovative platform combines the use of genetic and pharmacological profiling with metabolic imaging to enable other rapid assessment of potential older and useful drugs in HGG.

For further information or to find out about our 2015-2016 Research Project Grants, please see our website at:
www.cancerqld.org.au/page/research_statistics/cancer_research_project_grants/



THE FORGOTTEN CANCERS PROJECT

Focussing on the causes of less common cancers



What is this study about?

Research into less common cancers has been scarce, despite the fact that these cancers account for 46% of all cancer diagnoses in Australia.

The Forgotten Cancers Project will study the role of genes, lifestyle and early life environment in the development of less common cancers with the aim of improving prevention and treatment of these diseases in the future.

Are you eligible?

- ✓ Are you over 18 years old?
- ✓ Have you been diagnosed with one or more of our targeted cancers?
- ✓ Where you over 18 at the time of diagnosis?

Our target

To build a strong research platform we aim to get a total of 30,000 participants. This is made up of 1,000 participants for each of the targeted cancers and a family member.

What's involved?

It's an easy 2-step process that can be done online and by post:

1. Complete the questionnaires
2. Provide a saliva sample for DNA analysis

If I'm not eligible, can I still help?

You can still help by spreading the word and recruiting new participants to this important project.

Less common cancers

- Non-Hodgkin's Lymphoma
- Leukaemia
- Multiple Myeloma
- Kidney
- Bladder
- Stomach
- Brain
- Liver
- Oesophageal
- Pancreatic
- Endometrial (Uterine)
- Other rare cancers

For more information

If you are interested in learning more about the study or have further questions:

- Visit our website www.forgottencancers.com.au
- Send us an email at forgottencancers@cancervic.org.au
- Call us on **1800 068 289**



Brain Tumour Information Sessions 2014

Brisbane

May

Date: Tuesday, May 13
Time: 10.00am – 11.30am
Topic: **Living Well With Seizures**

July

Date: Tuesday, July 15
Time: 9.30am – 11.30am
Topic: **Physical activity and nutrition during and after treatment**

September

Date: Tuesday, September 9
Time: 10.00am – 11.30am
Topic: **A couples and family guide to managing the effects of brain tumour**

November

Date: Tuesday, November 18
Time: 10.00am – 11.30am
Topic: **Searching for meaning after a brain tumour**

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

Don't forget!



You can find many of our brain tumour podcasts at Cancer Council Queensland's website www.cancerqld.org.au



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

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.



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.

Regional office contacts:

Bundaberg

Ground floor,
312 Bourbong Street,
Bundaberg West
T: 07 4150 4500
F: 07 3259 8401

Cairns

169 Aumuller Street,
Bungalow
T: 07 4047 5500
F: 07 3259 8478

Gold Coast

1 Short Street,
Southport
T: 07 5503 3700
F: 07 3259 8457

Mackay

4a, 6-8 Discovery Lane,
North Mackay
T: 07 4842 2000
F: 07 3259 8371

Rockhampton

43 Upper Dawson Road,
Rockhampton
T: 07 4932 8600
F: 07 3259 8480

Sunshine Coast

Shop 4,
54 Baden Powell Street,
Maroochydore
T: 07 5451 6000
F: 07 3259 8479

Toowoomba

137 Herries Street,
Toowoomba
T: 07 4690 5800
F: 07 3259 8481

Townsville

24 Warburton Street,
North Ward
T: 07 4796 8400
F: 07 3259 8507



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.

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 0422 784 885, visit their website at www.braintumourhelp.com.au or find them on Facebook.

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 raise 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 12-24 who have cancer, have parents/siblings with cancer or parents/siblings who have 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

Support services for people affected by brain tumours continued

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.au/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

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 through 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/

Useful resources

Resources available through our Cancer Council Helpline. Call on 13 11 20 or 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 Oligodendrogliomas): 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)

Useful websites

- 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)
- 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

October 26 - November 1
International Brain Tumour Awareness Week

November 7
BrainChild Awareness Day



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