

Brain Tumour Support Service

Edition 3, 2015

Dear Friends,

Welcome to this third edition of the newsletter for 2015.



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

We have some excellent reading for you in this newsletter.

In **News & Events**, you'll find details of a new Sunshine Coast support group, a reminder about the BTAA consumer forum and an article on types of biomarkers.

In a **special Research Update**, you'll find details of some of the major research projects, including updates and information on how to take part in studies and clinical trials.

There's an update on the largest study of glioma in Australia, the Glioma Epidemiology Study. Glioma is the most common type of primary brain tumour found in adults.

There's also information about a **psychosocial study** into the impact of social networks on wellbeing after brain tumour. This study is being conducted by Lee Cubis, a Clinical Psychologist PhD student at Griffith University.

Another study on survivorship will hopefully enable us to have a greater understanding of the impact a brain tumour has on the patient and the carer long term. Survival rates for adults with brain cancer have improved over the last thirty years but little research has been done with families, friends or carers.

The final section included articles about research into childhood brain tumours, including questions to ask before joining a clinical trial, all very useful information.

'Till next time stay happy, keep well and keep smiling.

Anne

Volunteer Editor
Brain Tumour Support Service Newsletter

Winning at Life.

I am glad I moved to walking distance from the supermarket, now all I have to do to get the groceries is drive across the street!

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About the Brain Tumour Support Service

Information, referral and support to people who have a benign or malignant brain tumour, their families and friends.

The service provides:

- Information about brain tumours and treatments
- Referral to support and rehabilitation services as well as Cancer Council Queensland's practical support program.
- Regular meetings that provide opportunities to meet other people dealing with a brain tumour and hear health professionals discuss topics of interest
- Regular newsletters offering up-to-date information, stories and support.

Get in touch!

Call us on 13 11 20
Email us at askanurse@cancerqld.org.au
Visit us at cancerqld.org.au

13 11 20

Call 13 11 20 for cancer and brain tumour support information, emotional and practical support. Our cancer support advisors can also refer you to Cancer Council Queensland support programs and other community services.

This free and confidential service is available Monday to Friday 8am–6pm (excluding public holidays) and is provided thanks to the generous donations and support of Queenslanders

Donate now

Your donations help fund our research and support services for Queenslanders affected by brain cancer and benign brain tumours, including provision of the Brain Tumour Support Service.

Donate online at cancerqld.org.au or call our Donor Hotline 1300 66 39 36

New Sunshine Coast support group

There is a new support group for Sunshine Coast residents who have a brain tumour, as well as their partners and family members.

The group is an opportunity to connect with others who understand what it is like to live with a brain tumour. After two sessions, feedback has been positive, with comments including 'wonderful', 'supportive', and 'really helpful'.

The group meets every second month on the last Thursday of the month at Bloomhill Cancer Centre in Buderim. Partners or carers are very welcome to attend.

Contact Clare Howard, Cancer Support Coordinator at Cancer Council Queensland's Sunshine Coast office, for further details **(07) 5451 6000**.

BTAA Summit and Consumer Forum

Registrations now open

The Brain Tumour Alliance Australia (BTAA) is holding their third National Summit at the Cancer Council Queensland head office on Thursday 22 October 2015. BTSS will be facilitating the consumer forum and registrations are now open.

The interactive forum will take place from 12pm – 3pm, and includes a complimentary lunch with a presentation by Professor Martin van den Bent, a brain tumour specialist from the Netherlands. Professor van den Bent will also be presenting an update on emerging treatments for primary brain tumours at the Cooperative Trials Group for Neuro-Oncology (COGNO) conference that follows the BTAA summit.

After lunch, a panel of guest speakers will provide an update on research and supportive care, including time for questions. This session is open to all with an interest in brain tumours. For further details about this event and to register visit btaa.org.au/events

International Brain Tumour Awareness Week
25–31 October 2015

The 9th International Brain Tumour Awareness Week will be held from Sunday 25 October to Saturday 31 October. The International Brain Tumour Alliance encourages you to organise an activity which will contribute to increased awareness about brain tumours. You could organise a walk, a picnic, a morning or afternoon tea, or an information seminar. To find out more visit theibta.org/awareness-raising/

Types of biomarkers

The chart below, supplied by the American Brain Tumor Association, lists specific biomarkers and their possible roles in brain tumour diagnosis, prognosis and prediction of response to therapy and treatment.

Biomarker	What is it?	Advantages of testing	What type of tumour?
MGMT- MGMT or Methylation of the O6-methylguanine-DNA methyltransferase	MGMT is a protein that repairs errors in DNA. When the gene encoding MGMT is silenced by methylation, chemotherapy may be more effective because cancer cells cannot repair cellular damage.	Testing for the MGMT gene promoter has been used to identify whether or not a patient could benefit from the chemotherapy drug temozolamide. It is also useful in determining whether a patient is eligible to participate in certain clinical trials.	Anaplastic astrocytoma Anaplastic oligodendroglia Anaplastic oligoastrocytoma Glioblastoma Anaplastic gliomas
IDH1/IDH2	IDH1/IDH2 are key metabolic enzymes that help to produce energy for cells and have now been found to be mutated in additional cancers. The mutations in IDH1/IDH2 appear to alter the genetic regulation and programming of the tumour cells, causing them to continue to grow and divide and not develop into normal cells.	IDH1/2 mutation testing is performed as part of the diagnostic workup for many brain tumours. Identification of IDH1/2 mutations can help to confirm that a lesion is a tumour (and not some sort of inflammatory process), diagnose specific subtypes of tumours and provide useful information about the prognosis for that tumour type.	Occur mainly in low grade gliomas
1p/19q	The p-arm of chromo- some 1 and the q-arm of chromosome 19 are found in all cells, but are frequently missing in oligodendro- gliomas due to a deletion mutation	The 1p/19q test looks at genetic changes to chromo- some numbers 1 and 19 in tumour cells and whether these chromosomes are complete or have a section missing. If sections of 1p/19q are found missing, research shows this could mean better outcomes for people with some types of brain tumours.	Oligodendrogloma Anaplastic oligodendrogloma Oligoastrocytoma Anaplastic oligoastrocytoma
BRAF	BRAF is a gene that makes a protein called B-raf. The B-raf protein is important because it sends signals to help direct the growth of cells within our body. It is part of the MAP Kinase pathway, a longstanding cancer target. BRAF mutations are activating mutations, turning the gene on and enabling extra growth of cells.	Research has found that brain tumours (some types of grade 1 and 2 astrocytoma, including grade 1 pilocytic astrocytoma), especially paediatric gliomas, may have a fault with their BRAF gene. The "V600E" mutation in BRAF is a target of several drugs developed for treatment of melanoma. Individuals whose gliomas have a BRAF V600E mutation may benefit from these melanoma drugs (e.g. vemurafenib).	BRAF testing is only clinically useful in a few selected tumour types and is most commonly used to determine whether a tumour is a pilocytic astrocytoma. Typically, BRAF mutation are limited to paediatric gliomas.
EGFR- Epidermal Growth Factor Receptor	EGFR is a member of the epidermal growth factor family and key cell signalling protein that is crucial for tumour growth. The EGFR signaling pathway is thought to play a crucial role in how a GBM tumour develops, continues to grow and spread, and its resistance to therapy.	Most genes exist as two copies — one from mom and one from dad. In glioma cells, the EGFR gene is often amplified so that the cancer cells have many additional copies of this important growth factor. EGFR testing can determine the number of copies that exist in glioma cells.	GBM

Biomarker	What is it?	Advantages of testing	What type of tumour?
EGFRvIII	EGFRvIII is a mutated form of EGFR. It has been found in about 30% of glioblastoma.	EGFRvIII mutation turns on EGFR growth-factor signalling when it would otherwise be turned off. Like EGFR amplification, EGFRvIII mutations are associated with more growth-factor signalling and a rise in the number of glioma cells.	GBM
PTEN	The PTEN gene codes for the PTEN protein, a known tumour-suppressor genes. It is mutated in a large number of different cancers. The normal PTEN protein inhibits cell growth.	The PTEN gene is frequently mutated in glioblastoma. When patients with grade II or grade III astrocytomas acquire PTEN mutations, it may be an indicator that the tumour is progressing to become a grade IV glioma (secondary glioblastoma).	GBM Astrocytoma
TERT	The TERT gene encodes telomerase, an enzyme that produces protective caps at the ends of chromosomes. These caps are called telomeres, and they shorten as cells age, eventually causing cell death.	The mutations turn on the TERT gene, enabling cancer cells to keep their telomeres long. By maintaining long telomeres, glioma cells can divide indefinitely without aging and dying. These mutations are associated with better prognosis in patients with IDH-mutated gliomas, but with worse prognosis in patients with gliomas lacking an IDH mutation.	TERT mutations are found in 80% of glioblastomas and oligodendrogiomas, and 25% of grade II/III astrocytomas.
ATRX	The ATRX gene alters DNA conformation in order to regulate which genes are expressed and which are silenced. It is also important for maintaining DNA integrity.	Mutations in ATRX are observed in up to 80% of grade II/III astrocytomas, where they commonly co-occur with IDH mutation and are associated with extremely long telomeres. ATRX mutations may have prognostic importance, but whether this is independent of the effects of IDH mutation remains unclear.	Grade II/III astrocytoma Secondary glioblastoma
Akt3	Protein that is highly active in glioblastoma and which interacts with the additional glioma-relevant genes PIK3CA and PIK3R1.	Akt3 presence may indicate a resistance to standard treatment.	GBM

Research update

The Australian Genomics and Clinical Outcomes of Glioma (AGOG) epidemiology study

The largest study of glioma in Australia is currently recruiting newly diagnosed patients who are being treated at Royal Brisbane and Women's Hospital, as well as 15 other hospitals in NSW, Victoria, Western Australia and Tasmania. The aim of the study is to examine the genetic, lifestyle and environmental factors associated with glioma and outcomes after diagnosis.

Newly diagnosed patients and unaffected family members, specifically siblings and partners, are being invited to participate. Participants complete three long-established questionnaires and give a blood sample. They also give permission for the scientists to obtain their routinely collected health records. Factors of interest include smoking, alcohol, diet, medical history and occupation. The study findings will be pooled with similar studies overseas.

Glioma is the most common type of primary brain tumour in adults, accounting for more than 80% of brain and central nervous system cancers. Established risk factors for glioma are few: older age, male gender, ethnicity (Caucasian) and rare hereditary syndromes. High-dose ionising radiation (for example therapeutic radiation for childhood cancer), the only known preventable exposure, is responsible for a very small proportion of cases. The evidence regarding the association with non-ionizing

radiation, such as radio frequency electromagnetic fields from mobile telephones and high-power electricity lines, is contradictory and prone to bias.

Compared with other cancers, glioma is considerably understudied. This study is large enough to improve understanding of the mechanisms that lead to glioma and the factors that determine its progression. This new knowledge will drive the development of future interventions aimed at preventing this serious malignancy from developing, and improving outcomes after diagnosis. The data and biospecimen resource will also allow the Australian research community to take advantage of rapidly evolving genetic technologies.

The study is funded by Cancer Australia and is being run by the University of New South Wales in collaboration with Cancer Council Victoria, the University of Western Australia and the Lowy Cancer Research Centre.

If you would like more information, please visit agog.org.au

This update has been generously provided by A/Prof Claire Vajdic, Head, Cancer Epidemiology Research Unit, Centre for Big Data Research in Health, University of NSW.



Staying Connected After Brain Tumour

Changes in social networks and impact on wellbeing after brain tumour

People with brain tumours can often feel alone in their experience. Changes in physical abilities, communication, behaviour and mood may lead to loss of employment, inability to drive and less ability to attend social and leisure activities. The loss of valued social activity and relationships can mean that people's social network are depleted when they most need support.

If you have been diagnosed with primary brain tumour and are aged 18-85 years of age you are invited to participate in this project, which aims to gain a greater understanding of changes to social networks after a diagnosis of brain tumour. The study is being conducted by Lee Cubis, a Clinical Psychology PhD student at Griffith University with support from Cancer Council Queensland. The findings will inform interventions aimed at supporting social participation after brain tumour.

Your participation will improve our understanding of how people stay connected to important social networks, and the effect that this has on their health and wellbeing.

What is involved?

If you would like to participate, you will be asked to complete a 45 minute telephone interview. This will include a brief assessment of memory, language and attention; as well as questions about your demographic, general

health, your emotional wellbeing and participation in social activities before and after your brain tumour. If you live in South East Queensland and prefer to complete the interview in person, Lee will meet with you at a place of your convenience (e.g. at your home, a local library or at Griffith University).

How to take part:

If you would like to take part in this study or require more information, please contact Lee Cubis on 0438 208 783 or by email: lee.cubis@griffithuni.edu.au



Australian Clinical Trials website

Clinical trials test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with brain tumours.

Your doctor or nurse may suggest you take part in a clinical trial. You can also find out more about clinical trials, including information on brain tumour trials currently registered in Queensland, by visiting the Australian Clinical Trials website at australianclinicaltrials.gov.au

You can find clinical trials near you by using the website's Search for a Clinical Trial tool at australianclinicaltrials.gov.au/anzctr_feed/form

The Australian Brain Cancer Survivorship Study

The Australian Brain Cancer Survivorship Study is being conducted by researchers at Queensland University of Technology and Deakin University.

The purpose of the study is to gain a greater understanding of the impact that a brain cancer – specifically, a glioma – has on people and their families over the long term.

As survival rates for adults with brain cancer have improved over the last three decades, the number of long term cancer survivors is increasing. However, due to the relatively low incidence of glioma, limited research has been conducted with long term survivors or their family carers.

Research with cancer survivors more generally has shown that survivors frequently experience ongoing physical and psychosocial problems, and partners or informal carers also experience ongoing supportive care needs across the disease trajectory. The researchers anticipate that long term brain cancer survivors and their carers may experience additional survivorship issues due to neurologic or cognitive impairments resulting from the tumour or treatments.

This study will involve completing a single survey including items about the impact of the brain tumour

and its treatment on physical and psychological health, thinking and everyday life. For family carers, questions will ask about how they help the person with a brain tumour and its impact on them.

Brain cancer survivors across Australia and their carers are invited to participate. To participate, you must be an adult 18 years and over living in Australia who:

- has been diagnosed with any type of glioma (e.g. glioblastoma, astrocytoma) at least two years ago

OR

- is a family member or friend and the main provider of physical, psychological or practical support to an adult diagnosed with any type of glioma at least two years ago.

Survivors and carers will be able to participate either via a paper survey (mailed to them with a reply-paid envelope) or by completing an online survey at <http://survey.qut.edu.au/f/184646/7c13/>. All participation is entirely anonymous.

To find out more contact Danette Langbecker on (07) 3138 6123 or email d.langbecker@qut.edu.au



Questions to ask about participating in clinical trials and research

You may find this checklist helpful when thinking about the questions you want to ask your doctor, clinical trials or research nurse, or the research contact person.

Practical questions

- What are my chances of benefiting from this research?
- What are the risks to me?
- Will I experience any side effects? How will they be treated?
- Are there any tests involved?
- Do I need to stay overnight in hospital?
- Will I need to take time off work? Will being involved affect my day-to-day life?
- Can I receive any reimbursement of out-of-pocket expenses?
- Can I still participate if I need to travel interstate or overseas?
- Who will oversee my cancer care while I'm participating?
- Can I be involved in more than one study at the same time?
- If I join this study, will I miss out on other treatment opportunities later?
- Can I still take other medication or complementary therapies while I'm involved in the trial?
- How much time do I have to think about whether or not to join this trial or study?

Study background

- What is being tested in the trial or study and why?
- How many other people will be involved in this research?
- How long does the research last? For how long do I need to be involved?
- If I take some time to decide, will delaying the treatment affect how well it works?

Legal and ethical questions

- Has the study been approved by an ethics committee?
- Can you go through the participant information with me?
- Can I have the participant information in a different language?
- Will I be covered if anything happens to me while I'm on this study?
- How will my identity be protected while I'm participating, and who will have access to my information?
- What will happen with the results of the research?
- Who can I contact if I have a problem?

Checklist drawn from Cancer Council's *Understanding Clinical Trials and Research* booklet. To order a copy call Cancer Council 13 11 20 or visit cancerqld.org.au



Research and childhood brain tumours

Brainchild Foundation – current research grants

The Brainchild Foundation facilitates ongoing research into childhood brain and spinal cord tumours through its fundraising efforts. Since December 2014, the Brainchild Foundation has contributed \$175,000 towards several research projects including:

Establishment of patient-derived xenografts from paediatric brain tumours to facilitate a personalised genomic approach to treatment.

Dr Brandon Wainwright of The University of Queensland is conducting this study, which involves transplanting brain and spinal cord tumour tissue from affected children into immunodeficient mice. The purpose of establishing xenografts will allow researchers to study the genes of specific tumour tissue. With this information, the effectiveness of different drug therapies on specific types of tumour tissue can then be explored. This study relies upon the donation of tumour samples from patients who have had their tumours surgically removed. The tumour types that will initially be collected for the study include medulloblastoma and high grade glioma.

Advancing childhood brain tumour research through the Queensland Children's Tumour Bank.

Dr Andrew Moore of the University of Queensland Diamantina Institute was awarded a Brainchild Foundation grant for this study. Since 2008, the Queensland Children's Tumour Bank has made significant contributions to childhood cancer research globally. They make high quality tumour samples available to researchers worldwide, as this is a critical requirement in cancer research. Tumour that is removed during a child's surgery is donated to the Tumour Bank to be stored for future use. These precious samples are eventually used to facilitate significant research projects all over the world.

Modelling paediatric glioblastoma in mouse chimaeras.

Adjunct Associate Professor Jeffrey Mann from Monash University is conducting research to discover how paediatric glioblastoma develops, so that treatments can be developed. 'The term 'chimaera' means an organism composed of two or more genetically different tissues. In this instance, mice containing paediatric glioblastoma tissue. Previous research has identified specific mutations which act together within cells causing the development of paediatric high-grade gliomas. This study will bring this goal a step closer by developing models of the disease in mice, thus creating a source of living paediatric high-grade glioma tissue for researchers to utilise in further study of this tumour.

The Brainchild Foundation is proud to support these projects which will improve the outcomes for children diagnosed with brain and spinal cord tumours. We are very grateful to our generous donors and volunteers, without whom this would not be possible.



Children and research – joining a clinical trial



When parents discover their child is suffering a brain or spinal cord tumour, their concerns obviously turn to what treatment options are available.

This may include thinking about whether to join a clinical trial. For some parents the decision is easy. Other parents may have mixed feelings about consenting for their child to participate in a research study.

For those who are unsure, discussing the issue in depth with the oncology team before committing may help with any concerns.

It may be worth considering that without research, today's treatments would not exist and neither will tomorrow's cures. Also, oncologists will quite often prescribe a treatment protocol based on a study even if the child is not enrolled in a study. This is because, in many instances, the treatment protocol follows the best known treatment for a specific tumour at the time. Participating in a study means your child also contributes to the improvement of treatments for children affected by all types of cancer.

Tumour tissue donation is a very simple way to contribute to ongoing research that focuses on identifying the causes and characteristics of different cancers. When a brain or spinal cord tumour is surgically removed, a portion of the tissue is sent to pathology to be identified and a diagnosis confirmed. In the past, the remaining tissue would have been discarded. However, with the existence of tissue banks, this precious resource can

now be stored in order to assist in the future search for treatments and cures.

Whatever the case, all research proposals must be presented to an ethics committee for approval before they can proceed. This helps to minimise the risk of potential harm to those involved. The level of commitment required from volunteers may range from a 10 minute questionnaire over the telephone to a lengthy project involving treatment and examinations over weeks, months or years. For anyone invited to participate in a research project, it is important to fully understand the commitment required prior to consenting.

Through international collaboration, the benefits of research across the globe is reaching a far wider clientele than ever before. The oncology team at the Lady Cilento Children's Hospital are heavily involved in ongoing research studies with their overseas counterparts. Australian oncology teams are participating in studies being conducted not only by Australian research groups, but also groups in the United States, the United Kingdom and Europe. At any given time, there are 40–50 studies open in which the Lady Cilento Children's Hospital is involved.

This information has been generously provided by the Brainchild Foundation brainchild.org.au



Further information and support can be provided at any Cancer Council Queensland office throughout Queensland or by calling 13 11 20.

cancerqld.org.au