



australasian  
biospecimen  
network  
association

# BIO-BABBLE

AUSTRALASIAN BIOSPECIMEN NETWORK ASSOCIATION  
NEWSLETTER  
MAY 2020

## 2020 ABNA Committee

PRESIDENT: Anusha Hettiaratchi  
VICE PRESIDENT: Cassandra Griffin  
TREASURERS: Valerie Jakrot & Catherine Kennedy  
SECRETARY: Leanne Wallace

COMMITTEE MEMBERS:  
Samantha Cauburg, Nina D'Vaz,  
Wayne Ng, Ussha Pillai,  
Georget Reaiche, Helen Tsimiklis,  
Li Zhou.

## Brain Cancer Awareness Month

May is Brain Cancer awareness month and provides an opportunity to unite those working in brain cancer research and raise awareness of this insidious disease within the wider community. In 2010 Robyn Leonard, a tireless advocate of brain cancer research, launched the first Brain Cancer Action Week – supported by the Cancer Council NSW and Cancer Institute NSW. Since then it has grown to become Brain Cancer Awareness month, coinciding with other international awareness raising efforts.

Biobanks are an essential resource for Brain Cancer research and to ensure cohesion and collaboration in research Robyn established Australia's first biobanking consortium – Brain Cancer Biobanking Australia. ABNA is honoured to have Robyn contribute to our monthly newsletter, showcasing Brain Cancer Biobanking in Australia and New Zealand.

## Brain Cancer Biobanking Australia

by Robyn Leonard

Brain Cancer Biobanking Australia (BCBA) is a consortium of leading adult and paediatric clinicians and researchers dedicated to improving survival rates for brain cancer patients. BCBA was established in 2015 by consumer advocate, Robyn Leonard, following the death of her daughter, Lucie, from brain cancer at the age of 34. The BCBA consortium currently has 65 members and operates under the umbrella of the Cooperative Trials Group for Neuro-Oncology (COGNO) at the NHMRC Clinical Trials Centre, University of Sydney. The consortium model with its close ties to the clinical research community provides the ideal platform to foster multi-institutional and multi-disciplinary research collaborations.

Brain cancer with its dismal survival rates and debilitating physical and cognitive effects has a devastating impact on patients and their families. Brain cancer kills more children than any other disease and more adults under the age of forty than any other cancer (1,2). Brain cancer survival rates have remained virtually unchanged for decades (3). The aggressive biology of brain cancer and its resistance to therapy is a formidable clinical problem, yet it remains one of the most under-researched of all cancers with little known about its causes or how to treat it.

Robyn Leonard's daughter Lucie pictured here, was 34 when she lost her seven year battle with a grade 3 astrocytoma in 2012.

Robyn quickly became a passionate consumer advocate for brain cancer research and was inspired to create BCBA. Her vision was shared by leading brain cancer clinicians, researchers and biobankers across the country, who joined her pursuit to expedite researchers' access to tissue samples and data by networking and harmonising the disparate brain cancer biobanking operations Australia-wide.



Image credit: Robyn Leonard

## Brain Cancer Biobanking Australia

(continued from previous page)

Due to the rare nature of the disease it has always been difficult to obtain sufficient clinical samples to power the type of research that is going to achieve real breakthroughs.

In an effort to overcome this problem and maximise the materials available for research, BCBA has identified and networked Australia's fragmented brain cancer biospecimen collections, established the nation's first brain cancer tissue registry, and acts as a virtual hub to facilitate centralised online access to the specimens available in what is now a 20 member biobanking network. The interactive register provides a 'one stop shop' for researchers globally - allowing them to search and apply for the samples they need to build their projects. BCBA is not a biobank itself, nor is it the custodian of any biospecimens or data. The focus is on individual biobanks retaining their existing governance and access procedures while collaborating to provide brain cancer biospecimens and data for researchers.

BCBA is focused on maintaining the virtual biobank hub while initiating various innovative programs aimed not only at increasing the resources available for basic brain cancer research, but also improving the quality of care for brain cancer patients. The National Adult and Paediatric Brain Cancer Clinical Registry project is a case in point. Instigated in response to the lack of high-quality clinical data associated with collected brain cancer biospecimens, the registry project has developed into an ambitious collaborative effort to create a national collection of key data to enable a better understanding of the lifelong impact of a brain cancer diagnosis, and facilitate data driven improvements in brain cancer care and survivorship.

Other initiatives include, a rapid autopsy project, a collaboration with the Neurosurgical Society of Australasia to embed brain cancer biobanking into the system of all neurosurgical teaching units and a virtual care coordination platform to connect brain cancer patients to the resources and expert advice they need regardless of where they live or their circumstances.

BCBA has a charity arm - the Brain Cancer Collective (BCC) – established in 2018 to support its operations and projects. In addition to the fundraising efforts of BCC, financial resources are acquired through philanthropy and grant applications. However, it is the incredible level of support and voluntary input provided by the consortium members that allows BCBA to continue breaking new ground.

Please visit [www.bcba.org.au](http://www.bcba.org.au) for more information about BCBA or [www.braincancercollective.com.au](http://www.braincancercollective.com.au) for information on the Brain Cancer Collective.



**BRAIN CANCER  
BIOBANKING  
AUSTRALIA**

Ref 1: Australian Institute of Health and Welfare (AIHW) 2017. Australian Cancer Incidence and Mortality (ACIM) books. Canberra: AIHW. Five year averaged mortality for ages 1-39 (2010 – 2014).

Ref 2: Australian Bureau of Statistics (published 2012 – 2016), 3303.0 Causes of Death, Australia (2011 – 2015), 'Table 1.3: Underlying cause of death, Selected causes by age at death, numbers and rates, Australia, Ages 1 – 14 (2011 – 2015).

Ref 3: Australian Institute of Health and Welfare 2017. Cancer in Australia 2017. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW. Supplementary tables: Chapter 5 Survival and survivorship after a cancer diagnosis, Table A5.5: Survival trends for selected cancers, between 1984-1988 to 2009-2013; Feb 2017.

# A History of Brain Banking

by Cassandra Griffin

Brain tumours have some of the highest mortality rates of all cancers – more than two thirds of adults diagnosed with glioblastoma will survive less than two years post diagnosis. In children, brain cancer is the most common form of all solid tumours and responsible for the death of more children in Australia than any other disease.

Researchers are still plagued by an incomplete understanding of brain tumour biology, resulting in substantial hurdles in the translational pathway. Progress towards improved diagnosis and treatment are compounded by limited biological resources which include access to human brain tumour tissue samples, hampering large scale progress. Biobanks are therefore an invaluable resource for both neuro-oncology research programs and other neurodegenerative and CNS diseases.

Traditional samples banked following surgical resection are a valuable research tool, however they only allow researchers a limited insight into disease progression. Sequential blood collections can supplement this, however to complete the picture, and fully characterise end stage disease, post-mortem brain specimens are needed. Post-mortem brain banking provides researchers an opportunity to characterise the spatial and temporal heterogeneity of brain cancer, visualising a complete anatomical picture of disease spread and allowing for comparison with samples collected at diagnosis.

Brain Biobanking is not a new concept and has a checkered history spanning almost 400 years. The first known brain bank was curated by surgeon and anatomist Frederik Ruysch in the late 1660s in response to the Vanitas artistic movement. His collection was purchased in the early 1700s following recognition that anatomical collections were essential for the 'professionalism of the surgical arts'. This led to a booming business of private anatomy schools and concomitant trade in anatomical specimens – which included the rise in the black market economy of cadavers.

In 1752 the English parliament approved the Murder Act, allowing judges discretion to include post mortem dissection as part of their sentencing for murder, facilitating the legal provision of subjects for brain donation. The largest anatomical collection arising from these reforms belonged to the William Hunter and Hunterian Museum he curated is now housed at the Royal College of Surgeons in London. From this collection came one of the first recorded examples of neuropathological diagnosis – the recognition of deficient dura mater from a patient affected with Saint Vitus' Dance, a movement disorder now known as Chorea Minor.

## The Mark Hughes Foundation Brain Bank

by Cassandra Griffin

The Mark Hughes Foundation (MHF) is a charity formed in Newcastle by Mark and Kirralee Hughes following Mark's diagnosis with Brain Cancer in 2013. The MHF's mission is to raise much needed funds for research, to create awareness and support brain cancer patients and their families.

The MHF Brain Bank located in Newcastle is a collection banking samples from diagnosis, through treatment, recurrence and end stage cancer. Post-mortem samples are collected through a rapid autopsy protocol that requires samples be frozen within 4 hours of death, a process that involves a multidisciplinary team of biobankers, physicians, nursing staff, pathologists and technicians. The MHF rapid autopsy program works closely with donors and their families to ensure that specific donation pathways, with extensive contingency planning, are in place for each patient. This prepares the team to manage logistical challenges such as home deaths, sudden deterioration or the unavailability of medical practitioners at the time of death.

The MHF Brain Bank works with donors across the entire Hunter New England Local Health District, an area spanning >130,000 square km. This presents numerous challenges in terms of accessibility to rural palliative care, 24 hour medical services and patient transport. For this reason the post mortem interval, or time from death to freezing of tissue, is extended to 12 hours.

For further information please contact:  
Cassandra.griffin@newcastle.edu.au



## A History of Brain Banking

(continued from previous page)

Despite increased availability of subjects from which tissue could be collected, brain banking was still a challenging endeavour, owing in part to the limited progress made towards successful preservation of the organ, but also due to ethical conundrums stemming from the church's recognition of the brain as the 'place of residence of the human spirit'.

Following the secular removal of hospitals from the church during the French Revolution, dissection and brain banking were uncoupled from criminal punishment – paving the way for modern pathological diagnosis and the first scientific brain bank.

Sadly, during the 1900s one of the largest brain banks was the Hallervorden collection, established from victims of the extermination camps of Nazi Germany. Appropriately, the collection which contained upwards of 10,000 samples, was respectfully buried in 1990.

In the current climate, informed consent, along with strict adherence to principles of human ethics and good clinical practice are at the forefront of modern brain banking. As research continues it has been suggested that not only is brain banking of invaluable benefit to medical research, but also can have positive psychosocial implications for donors and their families, particularly in the paediatric setting. Work is being undertaken in this area both at the MHF brain bank (see text box on previous page) and other institutions to enable us to fully understand the benefits of brain biobanking for both research and our community.



### The Charlie Teo Foundation

by Nicole Caixeiro

Charlie Teo Foundation (CTF) is an Australian charity funding brain cancer research. CTF's research strategy uses a thesis-driven funding approach. To find out more about each thesis currently being funded please [CLICK HERE](#).

Charlie Teo Foundation Brain Tumour Bank (CTFBTB) was established under the More Data thesis – to produce and share high-quality, well-annotated, biological and clinical data that has the potential to drive further innovation and scientific breakthroughs.

CTFBTB collects samples of human tissue, live cells, DNA and blood to be used for brain cancer research. It is unique because not only does it collect tissue and blood samples, as routinely collected by Australian brain biobanks, but CTF determines the precise sequence of every nitrogenous base pair that makes up the genetic code of the patients who have donated their samples. This provides a highly comprehensive, cost-effective, time-saving and invaluable data resource for researchers to use to help advance research of brain cancer.

CTFBTB also has a cell line repository of real-world brain tumours. Researchers can apply to use these valuable and accurate models that enable more refined analysis of the mechanisms that regulate individual patient response to treatment and allow for the further development of models for precision medicine.

If you have any questions or are interested in applying for samples, please email: [research@charlieteofoundation.org.au](mailto:research@charlieteofoundation.org.au)



## Cancer Society Tissue Bank

by Helen Morrin

The Cancer Society Tissue Bank Christchurch (CSTBC) was established in 1996 and underpins cancer research using human specimens, with processes, practices and governance that is inclusive of our indigenous Māori people's cultural values to encourage participation from all communities.

In 2003 the CSTBC added the collection of brain tumours to its biobanking program with a focus on high grade gliomas preparing fresh frozen tissue, paraffin embedded tissue, serum, plasma and germline DNA, with clinical data. Paediatric gliomas were included from 2004.

This collection has been well utilized in a range of biomedical research from telomere maintenance mechanisms and prognosis, the role of vitamin c in brain cancer through to pre-clinical development of a cancer drug. Our biobank is committed to facilitating adult and paediatric brain cancer research and currently supports a prospective collection of gliomas.

For further information contact; Helen.Morrin@otago.ac.nz



## Brain Cancer Research Group, Kolling Institute

by Amanda Hudson

Dr Amanda Hudson, brain cancer researcher and lead author of "Glioblastoma Recurrence Correlates with Increased APE1 and Polarization Toward an Immuno-Suppressive Microenvironment" discusses the utility of biobanks relating to this research.

We are a translational research lab which means we take important clinical questions into the laboratory in order to investigate and find solutions for them. While laboratory models are useful to clarify certain questions, they do not always capture the complexity of the disease. The use of patient samples that are taken during the patient's cancer journey, can be more informative and truly capture the heterogeneous nature of the disease. Our recent research focused on how brain tumours change over time and as a result of treatment pressures with the hope that such knowledge will elucidate new treatment strategies. However, the ability to perform this project relied on the availability of uncommon matched tumour specimens collected longitudinally over a patient's journey.

Thankfully for us, tumour specimens corresponding with our specific criteria were available in our local biobank (Kolling Institute Tumour Bank). Analysis of these matched diagnostic and recurrent tumour specimens from numerous patients led to some very important findings.

Multiple different mechanisms were being used by the cancer cells to allow them to survive, suggesting a combinatorial therapeutic approach may be sensible to combat this terrible disease. For more information on this research, please follow the link [HERE](#).

Having access to biobank samples has been the crux of this research and will continue to be for future research projects. The knowledge gained from utilisation of banked tumour specimens will lead to better treatments for patients with this terrible disease, and with time even a cure. However, without biobanking to collect, curate and store these vital specimens, as well matching clinical information, such valuable resources so critical to finding this cure will be lost.



Dr Amanda Hudson -  
'Fight on the Beaches', a  
funder of Dr Hudson's current research.

## Australian Genomics and Clinical Outcomes of High Grade Glioma (AGOG)

by Anna Nowak

AGOG was established in 2008, funded for 5 years through a Cancer Council NSW STREP grant. Ambitious in scope, AGOG set about collecting fresh frozen tumour, serum, plasma, germline DNA, RNA and DNA extracted from tumour, and clinical data from patients with high grade glioma in Western Australia and New South Wales, overcoming barriers of multi-site tissue collection and storage, and the unpredictability of neurosurgical operations. As initial funding ended, AGOG investigators added a further focus; AGOG-Epidemiology, collecting epidemiological data in addition to clinical information, under the leadership of Professor Claire Vajdic.

Although AGOG collected and stored biospecimens and data on over 1000 individuals with these rare cancers, and has contributed samples and data to numerous projects, one of our greatest achievements has been to springboard a better networked brain cancer biobanking community.

Longstanding collaborations have been formed, AGOG leadership has worked closely with BCBA, and brain cancer biobanking is now recognised as a key research resource. AGOG is no longer collecting samples due to funding constraints. Information on the collection, availability, and access procedures is available through: [www.agogbio.unsw.edu.au](http://www.agogbio.unsw.edu.au) or [www.bcba.org.au](http://www.bcba.org.au)



## The New Zealand Brain Tumour Trust

by Janice Royds & Noelyn Hung

The New Zealand Brain Tumour Trust (NZBTT) has two core aims: the relief of suffering for patients and their families, and support for brain tumour education and research. We believe in fostering happy memories and making a positive difference to the lives of patients and their loved ones.

We started in 2016 as a group of friends and colleagues who had a passion to improve life for people with the diagnosis of a brain tumour and to offer hope for the future through research and clinical trials. As trustees we worked behind the scenes setting up both our Constitution and support groups around New Zealand. The Trust was officially launched with a fundraising event in Dunedin on September 13th, 2019 which was attended by New Zealand's Minister for Health, David Clark and our Patron Sir Richard Faull KNZM, FRSNZ.

The NZBTT has brought together a range of people who have personal experience of the condition, either through a family member, a close friend or as patients. We are also involved in increasing public awareness of brain tumours and in research. Biomedical research is the foundation that underpins the progress made in cancer care.

Our mission: to enhance the quality of life for people with brain tumours, their families and whanau, and to support medical research targeting brain tumour diagnosis, care and therapy. This is embodied in our motto "Ihi a Rangi", meaning the force of the spiritual realm underlying physical health, healing and wellbeing.



More information on NZBTT can be found at:  
<https://www.nzbtt.com/>

The authors would like to acknowledge the help from Wairangi Jones, a Pou Matu principle advisor from Tutira Mai NZ, in the development of the logo and motto.

## South Australian Neurological Tumour Bank/ SA Brain Bank

by Rebecca Ormsby

The South Australian Neurological Tumour Bank (SANTB) is a state-wide bioresource that is committed to providing researchers with high quality specimens linked with comprehensive clinical data in addition to facilitating research into the prevention, diagnosis and treatment of neurological cancers. We collect all neurological tumours that arise in the brain and spinal cord and this includes common and rare tumours as well as metastatic, pituitary and benign tumours. We collect fresh and frozen specimens plus pre-operative and post-operative blood samples which are stored as whole blood, plasma and buffy coat. In addition, we collect normal CSF as well as any normal (or non-pathological) brain tissue that is removed during surgery providing a valuable resource for researchers wanting to study the tumour microenvironment or to identify differences between tumour and normal tissue. We currently have specimens from over 400 participants banked.

The SANTB is also associated with the SA Brain Bank which collects post-mortem brains from donors with a range of neurological diseases including brain tumours. We currently hold 25 brains with brain tumours.

Any researcher who wishes to enquire regarding access to specimens can contact the Coordinator, Dr Rebecca Ormsby via email ([santb@flinders.edu.au](mailto:santb@flinders.edu.au)) or phone (08 8204 4393).



If you have any suggestions for a short article for Bio-Babble, please contact :  
[abna.biobabble@gmail.com](mailto:abna.biobabble@gmail.com)

Content deadline for June 2020 edition: 19.06.20