Quick Update:

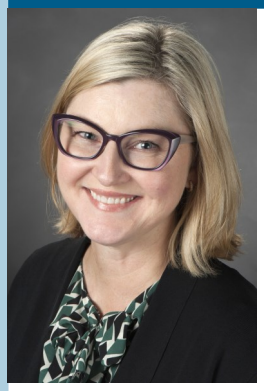
- Membership: 780 members
- 12th COGNO ASM Report
- Increasing trials portfolio

COGNO
COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

Member Newsletter

Issue 31 Summer 2019

Inside this issue:



Message from our Chair

Dear COGNO members,

At the end of the year, it's time to reflect on what we have achieved at COGNO in 2019. It's been an incredibly active year that has seen our capacity stretched in the best possible way.

The 2019 COGNO ASM took place over an intense three days in Sydney in late October, with Jonathan Parkinson and his team putting together a fantastic meeting with stellar international speakers. We are fortunate that this meeting always attracts invited speakers who are happy to give several talks, participate in panels, and lend their expertise to the open SAC meeting. Planning for 2020 has already started, with Sanjeev Gill and Rosie Harrup co-convening the Melbourne meeting.

The Australian Brain Cancer Mission continues to facilitate and drive activity at COGNO, with welcome additional funding enabling us to develop a number of new clinical trials. In the last 12 months, significant progress has been made towards opening CODEL, PersoMed-I, MAGMA, PICCOG, LUMOS, and the co-badged FIG study. These new trials will give COGNO and our patients the broadest trial portfolio yet, covering GBM, oligodendroglioma, low grade glioma, and medulloblastoma. As this newsletter goes to press, a call for research to improve quality of life and survivorship for brain cancer survivors will have just been released. In 2020, we will need the support of the entire COGNO community to ensure that these trials will recruit and succeed, helping to answer important questions for our patients and for the neuro-oncology community.

With our membership 'milestone' set to reach 800 members within the next couple of months, this is the perfect time to get more involved in COGNO activities and COGNO trials. Finally, wishing you all Merry Christmas, Happy Holidays, and Happy New Year.

Professor Anna Nowak
Group Chair

Save the Date!
13th COGNO Annual Scientific Meeting
Sunday 18th October - Tuesday 20th October 2020
Melbourne, Australia

Stay posted for further updates, or email cognoasm@ctc.usyd.edu.au to join our mailing list. Co-convenors A/Prof Rosie Harrup and Dr Sanjeev Gill are already working with the 2020 organising committee to develop another fantastic ASM.

12th COGNO Annual Scientific Meeting
The Neuro-Oncology Picture: Now and The Future
Sunday 27th October - Tuesday 29th October 2019
International Convention Centre Sydney, NSW, Australia

Congratulations to Dr Jonathon Parkinson (Convenor) and the 2019 Organising Committee on a successful Annual Scientific Meeting. International guest speakers Prof Colin Watts, Prof Ben Ellingson, A/Prof Helen Shih, A/Prof Seema Nagpal and Prof Ian Law were very well received, contributing not only to the scientific program but between them also to the Patient Education and Support Forum, The Brain Cancer Group Scientific Meeting and post ASM meeting, OzMRS Symposium.

Congratulations to our award and grant recipients:

- **MSD Hubert Stuerzl Memorial Educational Award** - Dr Ashray Gunjur
- **COGNO Outreach Education Preceptorship** - Dr Minjmaa Minjgee (Mongolia)
- **COGNO/Elekta Radiation Oncology Trainee Scholarship** - Dr Wee Loon Ong
- **COGNO Neuro-Oncology Nurse Care Coordinator Travel Grant** - Ms Elizabeth Campbell-Taylor
- **BTAA Lynette Williams Award first prize** - Ms Dianne Legge for her abstract "*Building the Bridge: The value of consumer co-design in brain cancer resource development*"
- **BTAA Lynette Williams Award second prize** - A/Prof Michael Back for his abstract "*Reflecting on survivorship outcomes to aid initial decision-making in patients managed for IDH-mutated Anaplastic Glioma*"
- **COGNO Young Investigator Award** - Miss Caterina Brighi for her abstract "*Disruption of the Blood-Brain Barrier using MR -guided Focused Ultrasound Increases Antibody Delivery to Non-Enhancing High Grade Glioma*"
- **COGNO Most Outstanding Oral Presentation** - Dr Sarah Shigdar for her abstract "*Targeted drug delivery reduces brain metastases*"
- **COGNO Most Outstanding Poster Presentation** - A/Prof Rosalind Jeffree for her abstract "*Developing a National Paediatric and Adult Brain Cancer Registry: A Clinical Feasibility Study*"

COGNO thanks our sponsors for their support of this year's Annual Scientific Meeting.

Platinum Sponsor: Cure Brain Cancer Foundation

Gold Sponsor: care2cure The Brain Cancer Group

Bronze Sponsors: Bristol-Myers Squibb; Roche

Other Sponsor: Australian Government Cancer Australia

Mr Luis Stuerzl, Dr Ashray Gunjur, and Mrs Wendy Stuerzl

Dr Sarah Shigdar

Prof Anna Nowak and
A/Prof Rosalind Jeffree

Mr Billy Williams and
Ms Dianne Legge

Mr Billy Williams and
A/Prof Michael Back

COGNO Outreach Education Preceptorship

Prof Anna Nowak, Dr Minjmaa Minjgee and A/Prof Zarnie Lwin

Report from 2019 Recipient, Dr Minjmaa Minjgee, Mongolia

It was my very first visit to Australia to attend the 12th COGNO ASM in Sydney which was an excellent opportunity to see Australian colleagues there who helped us to introduce Linear accelerator based conformal radiation therapy first time in Mongolia through APROSIG.

I am so pleased to have the grant to attend the ASM and the Preceptorship program and very grateful for this opportunity offered by the COGNO Outreach and Education Committee.

On the first day of the meeting I attended the Patient Education and Support Forum. Educational lectures for patients were impressive and I learned a lot about treatment and social issues happening in brain tumor patients and their families. This is not much developed in our country, most doctors think that it is the work of only psychologists and social workers.

In the next two days I have seen a best example of very effective and productive multidisciplinary scientific meeting of neuro oncology. I enjoyed hearing the latest advances and new technologies in diagnostic imaging, such as MRI, integrated PET-MRI, molecular imaging about some of which I've never heard before. Different opinions and evidences of neurosurgeons and medical oncologists practicing in different places was good to hear. It was interesting that surgical aggression depends on genetic analysis in individual patients and in general I understood that future practice will need to adapt to changes in tumor biology.

Another impressive thing was people from different specialties in neuro-oncology work together, and produce new ideas of research / clinical studies, share their information of ongoing and planned clinical studies with each other.

As we have just established our Neuro-oncology society, the COGNO meeting gave me a wonderful experience and inspiration. I really hope we will further learn from COGNO, and for possible collaboration.

The 2-day Preceptorship in the Liverpool Hospital was another memorable experience for me. Dr Eng-Siew Koh led this preceptorship with great effort with a full busy program which let me meet and learn from many members of the Radiation Oncology department with high standard.

I'd like to thank again the COGNO Outreach and Education Committee, namely Dr Zarnie Lwin, and Dr Eng-Siew Koh, for their time and effort, and Ms Jenny Chow and Ms Yi Feng for their kind help in administrative matters.

Dr Minjmaa Minjgee
Radiation oncologist, National Cancer Center of Mongolia
05 December 2019

COGNO/Elekta Radiation Oncology Trainee Scholarship

A/Prof Zarnie Lwin and Dr Wee Loon Ong

Report from 2019 Recipient, Dr Wee Loong Ong

As a radiation oncology trainee interested in neuro-oncology, I have recently attended the COGNO annual scientific meeting, thanks to the kind support of the inaugural COGNO/Elekta Radiation Oncology Trainee Scholarship.

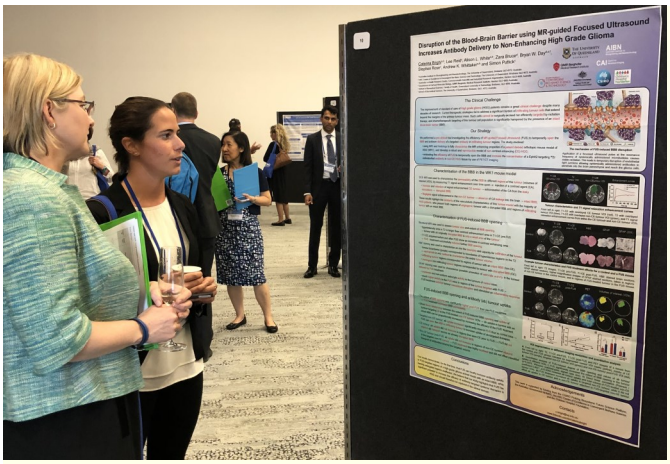
The COGNO ASM is a multidisciplinary meeting attended by clinicians, allied health workers and scientists involved in neuro-oncology research and clinical trials in Australasia. It was a two-day meeting jam-packed with abundant neuro-oncology gems to take away. It was refreshing listening to presentations by the esteemed international speakers, which covered various aspects of neuro-oncology, from imaging to surgery and radiotherapy. In particular, I found the presentations on the role of MRI and PET imaging in neuro-oncology by Prof Ben Ellingson and Prof Ian Law to be very useful. A/Prof Helen Shih, a radiation oncologist from MGH also gave several educational talks on managing pseudo-progression following treatment, and the role of radiotherapy in base of skull tumours. Prof Colin Watts' presentation on the role of surgery in the setting of recurrent glioma, and the ethical conundrum of whether to obtain tissue confirmation in this setting provided much food for thought.

The poster walkaround was a very friendly session, with opportunity to meet with various presenters, and discuss their presented research. The conference dinner at the end of the day was an enjoyable moment of professional networking which promoted collegiality among conference attendees. There were several awards presented at the dinner to acknowledge and celebrate the achievements of the researchers involved in neuro-oncology research in Australasia.

This was my first COGNO ASM, and I have thoroughly enjoyed it. I am grateful for the COGNO/Elekta Radiation Oncology Trainee Scholarship for supporting my attendance at the COGNO ASM. I walk away with renewed appreciation of not only the complexity in running neuro-oncology trials but also of how trainees can be more involved in COGNO at early stages of their careers. I would definitely recommend trainees interested in neuro-oncology to attend the COGNO ASM in the future!

Dr Wee Loon Ong
Radiation Oncology Trainee, Austin Health, Melbourne

Young Investigator Award



Prof Anna Nowak and Miss Caterina Brighi

Report from 2019 Recipient, Miss Caterina Brighi, on her poster presentation "Disruption of the Blood-Brain Barrier using MR-guided Focused Ultrasound Increases Antibody Delivery to Non-Enhancing High Grade Glioma"

Despite the extended efforts in developing new and more effective therapies, high grade glioma remains one of the most aggressive types of brain cancers with a median survival time limited to 14 months following current standard of care. A major challenge in improving prognosis is the inability of current therapeutic strategies to address a clinically significant burden of infiltrating tumour cells that extend beyond the margins of the primary tumour mass and cannot be surgically excised nor efficiently targeted by chemotherapy or radiation therapy. Therapeutic intervention for this population of cells is significantly hampered by the presence of an intact blood brain barrier.

The work presented at COGNO this year showed the result of a pre-clinical trial investigating the efficiency of MR-guided Focused Ultrasound to temporarily open the blood brain barrier and achieve delivery of a targeted antibody in infiltrating tumour regions. By use of in vivo MRI and histological analyses we fully characterised the MR enhancing properties of a patient derived orthotopic mouse model of high grade glioma and developed a robust and reproducible model of non-enhancing high grade glioma. Using this model, we evaluated the efficacy of MR-guided Focused Ultrasound to increase the concentration of a 89Zr radiolabelled antibody in non-enhancing tumour tissue by use of PET/CT imaging techniques. MR-guided Focused Ultrasound was shown to significantly increase both extent of blood brain barrier opening and antibody uptake in the non-enhancing tumour tissue in a directly proportional manner. Overall, we highlighted the potential of MR-guided Focused Ultrasound to change the clinical management of high grade glioma, creating new therapeutic possibilities for emerging therapies, including systemic therapies that have previously proved ineffective due to poor blood brain barrier penetration.

Miss Caterina Brighi
PhD student, University of Queensland

MSD HUBERT STUERZL MEMORIAL EDUCATIONAL AWARD REPORT

Report from Dr Arian Lasocki, recipient of 2018 MSD Hubert Stuerzl Memorial Educational Award

I was very fortunate to receive the 2018 MSD Hubert Stuerzl Memorial Educational Award, which gave me the opportunity to attend the annual meeting of the American Society of Neuroradiology (ASNR) in Boston, followed a short time later by a 4-week preceptorship at the National Hospital for Neurology and Neurosurgery (NHNN) in London.

First, in May I attended the ASNR meeting in Boston. I was also honoured to be invited to speak on radiogenomics in glioma (the prediction of genetic markers in gliomas based on MRI features), in the session organized by the AOSNHNR (Asian-Oceanian Society of Neuroradiology and Head & Neck Radiology). A strong focus at the meeting was artificial intelligence (AI) and, eventually after several lectures, I slowly gained some understanding of this complex and rapidly-evolving area. A strong message was that AI would improve our efficiency, in particular at performing routine tasks, rather than – fortunately – replacing neuroradiologists. I was especially interested in the use of AI in radiogenomics. AI methods such as deep learning have at times received criticism due to the difficulty in explaining the methods the system has used, but I was heartened to see that the underlying processes could be later interrogated to visualize the key features the system had identified.

En route to my preceptorship, I first attended the World Congress of Dermatology in Milan to present my research on intracranial melanoma metastases, my other main research interest. It was somewhat daunting to present a paper containing subtle neuroanatomical differences to dermatologists, but this also made it a very valuable experience. The conference was also a rare opportunity to learn more about the underlying pathogenesis of melanoma and attend comprehensive presentations on modern systemic therapies for melanoma – topics which are not covered at radiological conferences, but are very relevant to my role as chair of the melanoma brain metastases multidisciplinary meeting (MDM) at Peter MacCallum Cancer Centre.

Finally, I spent four weeks at the NHNN in London, a large quaternary referral centre for neurology and neurosurgery. It has a catchment of a large portion of north and northwest London, as well as, more importantly, accepting referrals from throughout London and the UK. To provide an idea of the scale of the service, reportedly there are about 70 consultant neurologists alone.

One of my main focuses was attending multidisciplinary meetings (MDMs). Indeed, there are so many, that attending MDMs alone could take up most of the week. In addition to prioritising the MDMs most relevant to neuro-oncology, I saw some incredible cases at MDMs in other neuroscience subspecialties, including a few diseases I had not previously heard of. The through-put of the service is truly astounding. For example, more than 50 cases are typically discussed weekly at the neuro-oncology MDM, and this doesn't include more sub-specialised MDMs such as the gamma knife, pituitary and spinal oncology MDMs. Reportedly, the concentration of MRI scanners in the small area around the NHNN is the highest in the world, with several hospitals and research centres in close proximity. Nevertheless, a large proportion of imaging reviewed at the MDMs is from external institutions, in particular from outside London. I face a similar issue in my own MDMs, and it was valuable observing how this was addressed.

It was also interesting to observe how the MDM differed in subtle but important ways to my own, related to the make-up of the team and the institution. In particular, in the context of intracranial metastatic disease (which makes up a substantial proportion of my practice), the treating oncologist was typically absent, thus decisions regarding the value of surgery and/or radiotherapy needed to be made with relatively limited knowledge of the systemic treatment options. I suspect this could lead to more conservative decisions. At my own MDMs, in particular in the context of metastatic melanoma, the presence of the patient's treating oncologist allows more nuanced discussions on not just the specific treatments, but also on the optimal combination and timing of these.

Coincidentally, the MRI scanners at the NHNN are similar to the scanner in my own department, providing an excellent opportunity to compare imaging protocols. I was interested in the strong focus on limiting sequences for certain indications, for example following-up some convexity meningiomas without IV contrast, which gave me food for thought. Another convenient coincidence was that the NHNN had recently rolled out the same electronic medical record software that will soon be installed at my institution, so I overheard some of the teething issues related to this transition. Finally, I was also fortunate to find colleagues with a similar research interest in the morphological patterns of glioma subtypes, which has led to research collaboration.

I am very grateful to COGNO and MSD for the amazing opportunities presented by the Hubert Stuerzl Educational Award. It was an incredibly rewarding experience, and the knowledge gained and relationships developed will provide benefit for years to come.

Dr Arian Lasocki
Neuroradiologist, Peter MacCallum Cancer Centre

Neuro-Oncology Nurse Care Coordinator Travel Grant

Report from 2019 Recipient, Ms Elizabeth Campbell-Taylor

This was the first COGNO ASM I have attended, thanks to a very generous Travel Grant provided by COGNO. Unfortunately I missed the Brain Cancer Patient Education and Support Forum on Sunday, as I was unwell, but caught up with the BTAA the next day. I think their patient materials would be greatly appreciated by patients, especially due to having so many specialists involved in their care.

For me, highlights included Ben Ellingson's presentation on MRI and treatment response, the case examples, Teletrials by Kate Burbury, and the Supportive Care sessions.

The Trial Updates were especially good and were relevant to me as I am involved with all the trials mentioned. I'm looking forward to being involved with the upcoming studies, and I was able to share my new-found knowledge with members of my team upon my return.

The COGNO ASM provided me with networking opportunities and pertinent education, new information, and study updates. It was a pleasure to attend this meeting and I hope to continue working in the area of neuro-oncology clinical trials and attend this meeting on a regular basis.

Ms Elizabeth Campbell-Taylor
Clinical Nurse Specialist
Haematology/Oncology Clinical Trials
Royal Hobart Hospital

2019 NATIONAL FLEECE COMPETITION

COGNO is immensely grateful to the Australian wool-growing community for their support of our research to improve health outcomes for brain cancer patients. Their generosity over the past 8 months has raised just over $30,000 for COGNO via individual donations, auction of a Merino ram, sale of donated lambs, and auction of donated fleece from the Australian Fleece Competition. Our heartfelt thanks to the organisers and key partners of the Australian Fleece Competition and Australian Sheep & Wool Show, Landmark, the Australian Sheep Breeders Association, the Australian Wool Testing Authority and of course to the Glen family, and friends and family of the late Gil Cochrane for nominating COGNO to be the beneficiary of this year's Fleece Competition.

Ken Yann and Rob Williams (Australian Wool Testing Authority), Candice Cordy (Landmark), Stephen and Connie Glen (Wattle Bank Merino Stud), Tess Cochrane (Axedale), and Mark Rosenthal (COGNO) at the auction of donated fleece.

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS

Associate Professor Rosemary Harrup

How did you become involved in COGNO?
I have been a member since the early days- about 2009. I have attended most ASMs and really enjoyed the collegial and relatively intimate atmosphere of all meetings. I was co-opted to the Management Committee in September last year and was elected for a three year term at the 2019 AGM - it has been a great Committee to work with and I am very grateful for the warm welcome I received.

Why did you become interested in Neuro oncology?
I grew up in a small country town and for some reason I always wanted to be a doctor! In early high school my close friend's father, a man I had known for years, developed a low grade brain tumour and I was a spectator to the trauma and devastation that this diagnosis brought to him and his family (much of which I didn't understand until I was older) with changes in personality and function which meant ultimately that they could no longer live together as a family unit. I still feel sad when I pass my friend's old house, one block from my parents' house each time I visit. Years later I was very fortunate in my first year of medical oncology advanced training to work with Mark Rosenthal and Lawrence Cher both of whom inspired me to continue an interest in Neuro oncology and provide support and treatment to patients and families affected by this awful condition.

What is a typical day for you?
I like to walk to work – one of the perks of living in Hobart! The 35 minutes (downhill all the way) gets me to work in a positive mood- it is more challenging in reverse at the end of a long day and sometimes I just treat myself to a taxi ride! I have clinics most mornings, wrangle emails before and after clinic and in the lunch break and then there is the admin off the side of the desk before I try to think of something for tea… (is it wrong to want to serve spaghetti bolognese more than once a week?).

What do you do in your spare time?
Spare time- what is that?? A husband, 3 teenagers and the six month old puppy…one of my favourite spare time occupations is swimming- my mobile has never rung underwater!

What are you most proud of in your career?
Building a local neuro-oncology service from the ground up in Hobart. The idea was originally born through the Tasmanian Late Effects clinic which commenced in 2009 in conjunction with Dr Greg Wheeler (paediatric radiation oncologist) and his nurse practitioner from PeterMac, myself and the paediatric oncologist. It was clear that the patient group with some of the most devastating late effects were the adult survivors of whole brain irradiation, often for prophylaxis or low grade glioma. These patients were discharged from follow up when they were deemed cured and then became lost in a huge uncoordinated piecemeal approach to multiple co-morbidities. Seeing their courage and tenacity (and often that of their aging parents) inspired me to commence a local Neuro Oncology service for the huge unmet need in our community for coordinated follow up and to put into action my learning from each COGNO meeting to ensure that the current generation of neuro oncology patients would receive the benefit of new (and less damaging) technologies, state of the art pathology, radiation oncology and medical oncology developments and of course access to clinical trials in brain tumour. I am very grateful for the support of my local colleagues, many of whom are now COGNO members in helping to build this service.

Mrs Desma Spyridopoulos

Desma Spyridopoulos joined COGNO in 2019 and is Chair of the COGNO Consumer Advisory Panel (CAP). She is a consumer representative member of the COGNO Management Committee, as well as the COGNO Scientific Advisory Committee.

Outside of COGNO, Desma is an experienced entrepreneur with a demonstrated history of understanding technical concepts and translating them for a wider audience. Starting as an art historian, she quickly discovered that her skillset had a more rewarding career in the growing technology sector. After working for start-up companies in the USA and Australia, Desma co-founded her own company in 2000, GLiNTECH, an IT consultancy in Sydney, where she leads Research and Special Projects.

How did brain cancer first touch your life?
In 2016, I was on holidays with my husband and three kids in Orange, NSW, when I received a call from my father's GP asking how quickly we could get back to Sydney. The CT scan (which was requested because my mum suspected his new 'fogginess' was the start of Alzheimer's disease) had come back and it looked like my dad had a large brain tumor. We drove back and took him straight to emergency at Prince of Wales. Within 24 hours, Dad had an MRI, was put on steroids, had seen a brain surgeon and had surgery scheduled. The surgeon's opening words to us were, "I've seen the scans. I'm really sorry". We were not dissuaded from fighting. My mum, brother and husband each took on a role in Dad's care. My role was to be the carer of his medical needs. At the time, we did not understand what the surgeon meant by "I've seen the scans. I'm really sorry." That was to become a constant refrain throughout my dad's patient experience as eventually we found out how bad his diagnosis was: Stage 4 Glioblastoma with recurrence 2 months post op.

How did you approach your role as carer?
Dad had answered the surgeon's refrain with, 'Let's see how far we can take this". I researched the changing symptoms of the disease to know what to expect and plan ahead. I aimed at a holistic view of Dad's treatment and had him trying complimentary therapies: weight training, psychology sessions, distance walking, dietary changes, completing puzzles, massage and meditation.

I knew that I would have to read as much literature as possible and explore every medical option for my father. As a layperson, this is not an easy task. Medicine is a very different industry and was unfamiliar, but I have changed industries before, I told myself. I inquired about every medical treatment I found, locally and internationally, and this exposed me to medical trials and their stages. I constantly triangulated results of our experience with other carers I had met and quickly became the go-to person in my circle to interpret information on any new drug/treatment.

Even with all the research, medically, Lomustine and Avastin were the only treatments for him in the end. This combination gave us time beyond the two-month life expectancy diagnosis. This time allowed Dad to fulfil his one bucket list item – an American stamp in his passport. Even with all this, the facts remained. He was changed - his personality altered, his mind never clearing, his mind-body connection was slowing down and his tumor was growing. Eventually he passed away 18 months after that first scan.

What lessons have you taken from your experience with your father, and how do you bring these to COGNO?
At work, I am the one tasked with finding solutions. But this is not a disease with a solution. Not yet. That was a hard, personal lesson.

Lesson two was that there is no standard experience of this disease. This was our experience: Dad did not have any seizures nor a second operation. Because of his age (72), the medical treatment was not as invasive or intense as that prescribed to younger patients and we were put on the My Aged Care and Palliative systems. These systems gave us access to services younger people may not receive. Also, Dad had retired comfortably so did not have to navigate a need to work. We had means, and were able to afford Avastin. Dad being older, though, meant we fought to have at least 'the standard of care' and not be sent home 'to get our things in order' - and thankfully our medical team listened. Living close to the hospital also made things easier; MRIs and tests could be scheduled at night, I was able to schedule appointments around work, and could be there with him the whole time to navigate the corridors and the building change at Randwick. Dad had a village supporting him at home. And we maintained a good quality of life for my father, considering his diagnosis.

I learned along the way that our experience is not a shared experience. The only commonality is an understanding that this disease has a lot of variability. Its stages, symptoms, cognitive and emotional responses, genetic make-up and medical treatment vary with each patient. It is a disease that is hard on both the patients and their main carers. It is a disease that changes you, eventually alienating you from those who knew you before diagnosis.

These are things I think about when reviewing scientific trial documents for COGNO. The CAP's role is to ensure patients and carers and their personal experience is considered, and that any information disseminated to them is easy to understand. Each CAP member joins with different experiences and all have been touched by the disease as a patient or a carer. My aim as Chair is to have as many 'consumers' views of the documents as possible. In 2020 I would love to grow the team to be more representative of the disease and locations within Australia so that we can capture the overall patient/ carer experience and more accurately respond to clinical trial documentation.

How do you stay motivated to continue your role?
a. The COGNO CAP team and my predecessor Robyn Leonard are a motivating, amazing group. I want to support them as much as I can.
b. I want to continue supporting carers and patients by interpreting information like I did while my dad was fighting this disease.
c. Through my personal submission to have Avastin listed on the PBS, I learned that, as patient advocates, our voices are heard. My plan is to continue having a voice through the COGNO CAP.
d. I also hope to witness changes in neuro-oncology, which has been traditionally slow to change.

STUDY & TRIAL UPDATES

CODEL (N0577): *Phase III Intergroup Study of Radiotherapy with Concomitant and Adjuvant Temozolomide versus Radiotherapy with Adjuvant PCV Chemotherapy in Patients with 1p/19q Co-deleted Anaplastic Glioma or Low Grade Glioma*

CODEL is an international, intergroup trial, jointly conducted by the Alliance for Clinical Trials in Oncology in the USA and the EORTC in Europe. COGNO will be participating under the EORTC umbrella.

As the title indicates, it is essentially comparing the efficacy of the Stupp protocol versus RT followed by PCV (procarbazine, lomustine, vincristine) in patients with both grade 2 and grade 3 oligodendroglioma.

Even though many clinicians already are using temozolomide in their practice, retrospective studies (particularly the 1000 patient Lassmann et al study) demonstrate PCV has a potentially superior survival to the temozolomide cohort, which is why this is still an important clinical question requiring an international effort to answer definitively.

The trial aims to recruit 360 patients internationally and 36 in Australia across 10 sites. Selected sites are in various stages of completing the required USA regulatory requirements and IROC credentialling as part of the RT Quality Assurance requirements.

CODEL has recently received ethics approval and we are waiting on the contracts to be executed, so that the trial can open in Australia. The trial is already recruiting patients in the USA.

The CODEL Trial Operations Coordinator is more than happy to provide any information that you may require on this study. Please email codel@ctc.usyd.edu.au if you have any queries.

LUMOS: *Low & Intermediate Grade Glioma Umbrella Study of Molecular Guided TherapieS*

Low and intermediate grade brain tumour are universally fatal brain tumours with almost no access to clinical trials. LUMOS is a comprehensive Australian trials program for these patients. We will match tumours on a molecular level with the best treatments. We will assist in accessing these drugs, including creating trials of new treatments. Lastly, we will collect an invaluable set of tissue and blood before and after treatment for future research into better treatments.

LUMOS has recently received HREC approval for the pilot study and will be aiming to open in early 2020.

Please email lumos@ctc.usyd.edu.au if you have any questions.

MAGMA: *Multi-Arm GlioblastoMa Australasia trial*

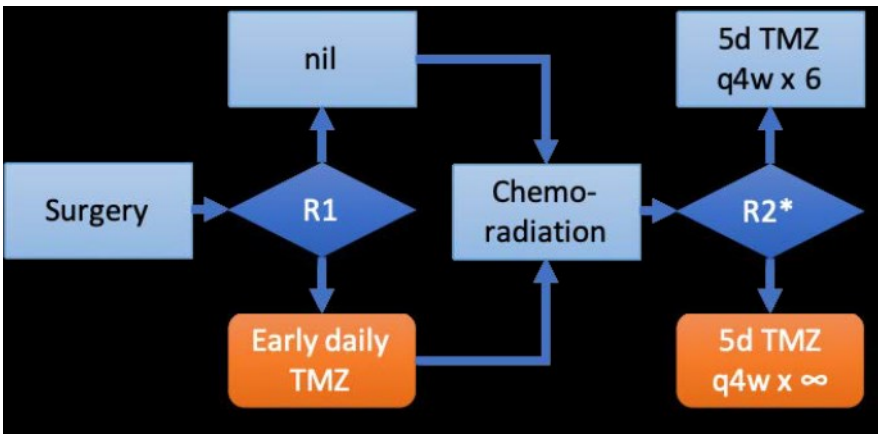
As announced in the Autumn COGNO Newsletter, the MAGMA trial (Multi-Arm GlioblastoMa Australasia trial) was successfully funded $2.5M over five years from the Medical Research Future Fund (MRFF). A nationwide team of COGNO members led by A/Prof Craig Gedye have been working to develop the protocol and it was submitted to HREC in Q3 2019. We are hoping to gain ethics approval, early in the new year.

MAGMA is a randomised, multi-arm, multi-stage phase III clinical trial. The study will focus on two aims to start and further questions and arms will be added as the trial progresses. The MAGMA trial will be designed to fit easily into your routine practice, with simple interventions and parsimonious data capture. The two initial arms are to:

1. Assess the efficacy of neoadjuvant (pre-radiation) TMZ compared with standard chemoradiotherapy in GBM and IDH-wildtype high grade glioma
2. Assess the efficacy of prolonged (treatment-until-progression) adjuvant TMZ chemotherapy compared with standard chemoradiotherapy in GBM and IDH-wildtype high grade glioma

Consenting participants will be allocated to treatment in a partial factorial design with optional randomisation. For each treatment question, patients will be randomised to a specific arm, unless they specifically choose not to participate in that randomisation, in which case treatment will be at patient/physician's discretion. As an example, the partial factorial design for the initial two questions of interest is outlined below.

StuStudy schema:



*NB: If a patient choses not to participate in a randomisation, then their standard treatment choice is in black text; R2 may occur at any time after R1 up until initiation of adjuvant TMZ. Only those patients randomised to at least one treatment question will be included in the primary analysis. Data from patients not randomised to either question will be collected and may be used in exploratory analyses.

Patients will be randomized upon receipt of histopathological confirmation of eligibility. The planned initial sample size (for these first 3 arms) of 300 patients can be recruited nationally in 3 years.

The key inclusion criteria are as follows:

1. Adults, aged 18 years and older, with newly diagnosed histologically confirmed grade 4 malignant glioblastoma or IDH-wildtype grade 3 high grade glioma
2. Adequate recovery from surgical resection
3. ECOG performance status of 0-2

Please email magma@ctc.usyd.edu.au if you have any queries.

ACED (COGNO14/02): *Acetazolamide plus Dexamethasone versus dexamethasone alone in recurrent and/or progressive HGG*

As you may be aware, the decision was made to close recruitment to the ACED study following the recent listing of Avastin (Bevacizumab) for glioblastoma on the Pharmaceutical Benefits Scheme (PBS) in August. This new indication has impacted ACED's recruitment potential. The Trial Management Committee felt that while the clinical question is still of importance, it is no longer a viable option to continue the trial to reach the recruitment target. There were no safety concerns for the participants.

The final accrual for the study was 30 participants. Please ensure that all data has been entered in the database and any diaries have been sent in. Activities to finalise data collection and site close-out are underway. The data will be fully utilised for presentations and publications.

The ACED Study Team would like to sincerely thank all the sites, participants and their caregivers and families for their generosity and support.

No.	Site Name	State	Principal Investigator	Site Status	Site Activation	# Patients Randomised
1	Liverpool Hospital	NSW	Eng-Siew Koh	Active	24-Jun-2016	14
2	Royal Brisbane and Women's Hospital	QLD	Zarnie Lwin	Active	30-Sep-2016	4
3	St Vincent's Hospital, Melbourne	VIC	Anthony Dowling	Active	14-Nov-2016	3
4	Epworth Healthcare	VIC	Ross Jennens	Active	20-Feb-2017	0
5	Sir Charles Gairdner Hospital	WA	Anna Nowak	Active	04-Apr-2017	3
6	Royal Hobart Hospital	TAS	Rosemary Harrup	Active	28-Aug-2017	3
7	Prince of Wales Hospital	NSW	Elizabeth Hovey	Active	16-Nov-2017	1
8	Chris O'Brien Lifehouse	NSW	Hao-Wen Sim	Active	12-Dec-2017	2
9	Flinders Medical Centre	SA	Ganessan Kichenadasse	Active	17-Jan-2018	0
10	St George Hospital	NSW	Tracey Dunlop	Active	14-Feb-2018	0
11	St Vincent's Hospital, Sydney	NSW	Cecelia Gzell	Active	20-Dec-2018	0
Total Recruitment						30

VERTU (COGNO14/01): VEliparib, Radiotherapy and Temozolomide trial in Unmethylated MGMT Glioblastoma. *A Randomised Phase II study of veliparib + radiotherapy (RT) with adjuvant temozolomide (TMZ) + veliparib versus standard RT + TMZ followed by TMZ in patients with newly diagnosed glioblastoma (GBM) with unmethylated O (6)-methylguanine-DNA methyltransferas (MGMT)*

Congratulations to Mustafa Khasraw for presenting the VERTU trial at the Society of NeuroOncology (SNO) conference in Phoenix, Arizona. It was a huge accomplishment to be awarded an oral presentation at this conference. The VERTU trial also featured in the SNO Daily Highlights, in which invited discussants review the most cutting-edge science from that day's basic science and clinical research presentations. The SNO Daily Highlights was video-taped and made available for viewing that same evening via the meeting app and social media. We would also like to extend our thanks to all site staff for their continued support in ensuring VERTU data is up to date.

We are continuing to follow participants in the follow-up phase of the study until all study endpoints have been reached. The VERTU Trial Coordinator is more than happy to provide any information that you may require on this study. Please email vertu@ctc.usyd.edu.au if you have any queries.

NUTMEG (COGNO16/01): *A Randomised Phase II Study of NivolUmab and TeMozolomide vs Temozolomide alone in newly diagnosed Elderly patients with GlioblastoMa*

The NUTMEG trial aims to recruit 102 patients across up to 20 sites. Currently 17 out of the 20 selected sites have opened to recruitment, with 45 patients randomised onto the NUTMEG trial across all sites as of the 19th of November 2019.

Since last update, we welcome Dr Ganessan Kichenadasse and their team at Flinders Medical Centre, Dr Sagun Parakh and their team at Monash Medical Centre and Dr Hui Gan and their team at Austin Hospital. Recruitment has remained stable over the past couple months with between 2-4 patients randomised per month. We are hoping with the new sites that have come on-board and with the activation of the remaining sites in start-up, recruitment will continue to pick up.

The NUTMEG Trial Coordinator is more than happy to provide any information that you may require on this study. Please email nutmeg@ctc.usyd.edu.au if you have any queries.

NUTMEG - PARTICIPATING SITE STATUS

No	Site name	State	Principal Investigator	Site status	Site activation	# Patients registered	# Patients enrolled
1	Royal North Shore Hospital	NSW	Michael Back	Active	22/02/2018	17	14
2	Prince of Wales Hospital	NSW	Elizabeth Hovey	Active	04/09/2018	1	1
3	Chris O'Brien Lifehouse	NSW	John Simes	Active	29/06/2018	2	1
4	Wollongong Hospital	NSW	Daniel Brungs	Start up	Pending	N/A	N/A
5	Gosford Hospital	NSW	Matthew Wong	Active	18/09/2018	3*	3
6	Campbelltown Hospital	NSW	Annette Tognela	Active	19/02/2018	5	5
7	Port Macquarie Hospital	NSW	Stephen Begbie	Active	21/01/2019	3	1
8	Newcastle Private Hospital	NSW	Craig Gedye	Active	27/03/2018	1	1
9	Peter MacCallum Cancer Centre	VIC	Kathryn Field	Active	28/08/2018	1	1
10	Epworth Healthcare	VIC	Ross Jennens	Active	10/09/2018	5	5
11	Austin Hospital	VIC	Hui Gan	Active	22/07/2019	1	0
12	Monash Medical Centre	VIC	Sagun Parakh	Active	17/06/2019	0	0
13	Royal Brisbane and Women's Hospital	QLD	Zarnie Lwin	Active	19/02/2018	8	5
14	Princess Alexandra Hospital	QLD	Katharine Cuff	Active	28/05/2018	4	3
15	ICON Cancer Care Wesley	QLD	Paul Eliadis	Start up	26/11/2019	0	0
16	Flinders Medical Centre	SA	Ganessan Kichenadasse	Active	12/06/2019	0	0
17	Royal Adelaide Hospital	SA	Hien Vinh Le	Active	22/1/2019	4	3
18	Sir Charles Gairdner Hospital	WA	Anna Nowak	Start up	05/04/2019	4	2
19	Royal Hobart Hospital	TAS	Rosemary Harrup	Active	31/05/2018	0	0
20	DUKE University Medical Centre	USA	Margaret Johnson	Start-up	Pending	N/A	N/A
Total recruitment						**59**	**45**

***Includes patient's transferred from other sites**

NEW CONCEPTS/TRIALS IN DEVELOPMENT

Do you have an idea for a potential study?

The COGNO SAC (Scientific Advisory Committee) meets via teleconference 3 times a year, and hosts an open, face-to-face meeting during the COGNO ASM. During the SAC meeting, new protocols are presented both by the proposer and also by the COGNO-appointed scientific and consumer reviewer/s before a wider discussion by the Committee.

If you have a great idea you are welcome to contact the COGNO SAC to discuss how we can assist in concept development.

If you become aware of a funding opportunity during the year which might be of relevance to COGNO, or for which you would like to involve COGNO in your application, please do let us know! Under these circumstances, we can facilitate urgent COGNO SAC review and COGNO input to assist you in refining your proposal, building your team, and hopefully improving your chances of a successful application.

If you require any further information please email candace.carter@ctc.usyd.edu.au.

A/Prof Hui Gan and Dr Eng-Siew Koh, on behalf of the COGNO SAC and COGNO community

ASM international guest speakers Colin Watts, Ben Ellingson, Seema Nagpal and Helen Shih with SAC members at the open SAC meeting in October.

ADDITIONAL INFORMATION

New Brain Tumour Resources

BTAA in association with Cancer Australia has co-funded a project to develop and distribute new brain tumour resource materials, and translate them for culturally and linguistically diverse (CALD) communities.

"My Brain Tumour Pathway" is a form for patients, which sets out details of their specific brain tumour, the treatments they will be having and the contacts to assist them in their journey. The form can be completed with help from their neurosurgeon, oncologist and/or brain tumour coordinator following the diagnosis of a brain tumour.

"It's Okay to Ask" is a booklet of questions about a brain tumour diagnosis, what to expect, symptoms, and treatment. Patients can use it when speaking to their oncologist, neurosurgeon and/or brain tumour coordinator.

The two new resources have been translated into the following languages:
- Arabic
- Simplified and Traditional Chinese
- Greek
- Italian
- Vietnamese
- Tagalog
- Hindi
- Punjabi
- Dari
- Spanish

A flyer has been prepared for clinician's use to advise patients of the availability of the two new resources in the different languages.

Additionally, the project identified an existing North Eastern Melbourne Integrated Cancer Service (NEMICS) video involving three high-grade glioma patients' stories, which was also translated using subtitles and can be accessed in the same locations.

The new materials have been placed on the BTAA website and are easily downloaded and printed in whichever language is required at https://www.btaa.org.au/resources/languages. Medical staff are encouraged to provide and complete the new information in the language of choice for patients and their families.

For more detail contact btaa@shout.org.au.

Brain Tumour Support & Education Forum May 2019 Talks

Talks from the Brain Tumour Support & Education Forum hosted by CINSW NNOG in Sydney in May 2019 are now available online at https://www.youtube.com/playlist?list=PLANQ5zQVFnQ3CopZh3CJxFMGxgm4JMR7e.

MEMBERSHIP UPDATE

COGNO now has 780 members! Help us expand our Group's expertise and networking capacity. If you know someone who would like to join, you can refer prospective members to our online membership application on our website (www.cogno.org.au) or office (cogno@ctc.usyd.edu.au).

COGNO STAFF UPDATE

There are a few changes to the Clinical Trials Operation team since our last update. We have farewelled Marzena Kelly and Lauren Fisher as both have left to go on maternity leave. We wish you both all the very best for a safe delivery and look forward to hearing of your baby news in the near future. Thank you for all your hard work on the CATNON, VERTU and NUTMEG trials.

Tara Flores will be taking on the role as the VERTU Trial Coordinator and Tracy Liaw will be the new NUTMEG Trial Coordinator. Both have both been working on the trials behind the scenes to ensure a smooth transition.

We welcome Stephanie Hollis to the COGNO team. Stephanie has been with the NHMRC CTC Oncology team as Trial Operations Coordinator for the past year and will be taking on the role as the Trial Coordinator for the CODEL trial. She has a background in traumatic brain injury research, completing her PhD in sport-related concussion and completing a Master of Medical Science in forensic brain injury. Over the past 16 years, Stephanie has been in research fellow roles with The George Institute for Global Health (Critical Care & Trauma) coordinating a US-funded study investigating mild traumatic brain injury; the University of NSW coordinating a study evaluating the implementation of an emergency rapid response system across NSW hospitals; and Hunter New England Health (with Justice Health) coordinating the forensic head injury study. Stephanie has also spent time with NSW Health as program manager for improving data linkage operations in the Centre for Health Record Linkage.

We also welcome Anneliese Lineaker and Hayley Thomas.

Anneliese has been working at the CTC as a clinical trials assistant with in the ANZGOG collaborative group for the past year. In her previous role she was working in IVF treatment with Monash University. Her university background is in public health and health promotion and is looking forward to developing more skills within the COGNO group in the future.

Hayley is new to the CTC and is working as a Clinical Trial Assistant for both the ANZUP and COGNO groups. Prior to this she was working as an Optometrist in private practice. Her first taste of clinical research came from the 2 years she spent in The UK, working at NIHR Moorfields Clinical Research Facility where she screened and recruited patients for ophthalmic trials and performed imaging and other optometric testing on trial participants. In addition to this she completed an Honours project on diabetic eye disease whilst studying at the University of NSW. Hayley is looking forward to learning more about clinical trials and developing new skills as part of the COGNO team.

Danielle joins the COGNO team as Project Officer. Originally from the U.S, now living in Australia, Danielle's background is in Higher Education. She has worked at Universities both overseas and here in Sydney providing administration, education and project support to various departments. Her interest in project support really developed while working for a consulting firm that partnered with organisations across the NGO, government, and private sector. When not at work, Danielle has many creative endeavours which include sewing, collage, drawing and jewellery making.

REMINDERS

- The September issue of the SPRC Newsletter is now available on the website, https://www.rcpa.edu.au/Library/Practising-Pathology/Structured-Pathology-Reporting-of-Cancer/Newsletters
- 22-24 July 2020: PROMS 2020 Conference, Abercrombie Business School, University of Sydney, https://sydney.edu.au/science/our-research/research-areas/psychology/sydney-quality-of-life-office.html
- 25 - 28 Aug 2020: AGITG 22nd Annual Scientific Meeting, Sofitel Melbourne on Collins, https://asm.gicancer.org.au/
- 18 - 20 Oct 2020: 13th COGNO Annual Scientific Meeting, Melbourne, https://cogno.org.au/content.aspx?page=cognoasm-home

Please note the COGNO office will be closed from 5:00pm Friday 20 December 2019 and will re-open at 9:00am Tuesday 7 January 2020. Wishing everyone a Happy Festive Season and New Year.

COGNO
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A/Prof Georgia Halkett (Treasurer)
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