Quick Update:

- Membership: 470 members
- ASNO-COGNO Scientific Meeting 2016 update



lssue 21

Autumn 2016



Message from our Chair

Dear COGNO members,

Nothing delights me more than the email notification from Jenny Chow, our Executive Officer, telling me that another COGNO Newsletter is about to be circulated and she is waiting for my "Message from our Chair". For this newsletter, I am especially pleased to write a few words as there is lots to tell and it is an exciting time for our Group. This newsletter highlights a number of significant events and achievements.

The annual scientific meeting of the Asian Society for Neuro-Oncology is coming our way in early September and will be held in conjunction with our own ASM. The Convening Committee has put together a terrific program and there will be plenty of international and national "stars" to learn from.

At the same meeting, we will re-energise the Hubert Stuerzl Memorial Educational Award which is sponsored by MSD and awards a \$15,000 prize to a young cancer specialist with an interest in neuro-oncology. This allows them to attend a major brain cancer conference and undertake a "preceptorship" at a major international centre of their choice. The prize has been awarded since 2007 but I felt it had lost its reference to Hubert Stuerzl, the original product manager for Temozolomide in Australia. It may seem odd that the award is named after a pharmaceutical product manager, but Hubert was the right person at the right time: providing free temozolomide to hundreds of patients, supporting education meetings and circulating hundreds of copies of a patient focused book on brain cancer. In my view, Hubert played a serious role in bringing neuro-oncology into the mainstream of cancer medicine.

You will read of three important pieces of information regarding trials. First, the initial results of the critical international CATNON study have been released and I'm proud to say that COGNO sites achieved 11% of world-wide accrual. Further, the personal contribution to the CATNON study of Anna Nowak and Helen Wheeler is recognised by their status as authors on an oral abstract presentation at the forthcoming ASCO meeting; a very prestigious achievement and congratulations are due. Secondly, through perseverance, tenacity and boundless energy, Mustafa Khasraw has ensured that the VERTU study is now up and running for patients with de novo GBM that have Unmethylated MGMT. And third, the ACED study is also about to start recruiting.

Finally, enjoy the bio on Siew Koh, I learnt a lot I didn't know. But to know her really well requires a dinner date with her and a few colleagues and see how you go trying grab a menu off her and make your own decision about what you want to order. Siew likes to take control...even I acquiesced.

Mark Rosenthal Group Chair

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MSD HUBERT STUERZL MEMORIAL EDUCATIONAL AWARD 2016

COGNO is pleased to call for applications for the MSD Hubert Stuerzl Memorial Educational Award 2016. The closing date for applications is **Friday 3 June 2016**.

The purpose of this award is to encourage education and training in the field of Neuro-Oncology and will provide up to \$15,000 for the successful recipient to:

- Attend an international Neuro-Oncology scientific meeting
- Undertake a Neuro-Oncology Preceptorship during 2016-2017

The Award is open to applications from individuals with a clear interest in the field of Neuro-Oncology and includes:

- Advanced Trainees in Medical Oncology, Radiation Oncology and Neurosurgery
- Medical Oncologists, Radiation Oncologists and Neurosurgeons of no more than 5 years standing who are enrolled in full-time post-graduate research (PhD or MD)

The award will be presented at the ASNO-COGNO Scientific Meeting 2016. Further details are available at (<u>http://www.cogno.org.au/content.aspx?page=msd-oncology</u>).

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS



Dr Eng-Siew (Siew) Koh is on the COGNO Management Committee (Secretary) and is the current Deputy Chair of the COGNO Scientific Advisory Committee (SAC). Siew has also Co-Convened the 2011 and 2013 COGNO ASMs. She is the current Chair of the COSA Neuro-oncology group. Siew

is working as a Radiation Oncologist based at Liverpool Hospital, NSW. After training at Westmead Hospital, she undertook a three year Fellowship at Princess Margaret Hospital, Canada, developing sub-specialty interests in adult and paediatric neuro-oncology.

How did you become involved in COGNO?

After returning from my Canadian Fellowship, I attended the 2008 COGNO ASM and witnessed our fearless leader Professor Rosenthal engage in a particularly shall we say 'robust' debate with another speaker. I thought to myself - this is definitely a cooperative trials group to be a part of! In all seriousness, it is great to be a part of a dynamic collaborative clinical trials group where every member can make a contribution.

Why are you still a COGNO member, 8-9 years on?

The COGNO community, with its niche beginnings, continue to grow and strengthen since its inception in 2007. Despite the breadth and depth of disciplines and consumer advocate community that COGNO represents, I am continually encouraged by its unity and purpose in advancing outcomes for those affected by brain tumours.

The 2009 COSA ASM at the Gold Coast which interfaced with the COGNO ASM was a definite highlight, with Roger Stupp and my Canadian mentor Normand Laperriere as keynote speakers. It was particularly personally rewarding to mentor a brilliant young medical student and see her win the 'best of the best' oral neurooncology abstract prize. This speaks to the wonderful opportunity we have to mentor our junior colleagues who in their own right one day in the future will make an important contribution to healthcare delivery and research.

Why did you become a Radiation Oncologist and why did you choose neuro-oncology?

Radiation Oncology represents all my favourite elements of health - challenging clinical cases, imaging, psychology, dealing with families, interfaced with everemerging technology and diagnostic advances, working in multi-disciplinary teams - enmeshing all these elements all into one.

I have been fortunate to have developed a wonderful collegial network, both across ANZ and internationally. At South West Sydney, we have strong collaborative links with Brain Injury and Psycho-social Researchers so we cross-pollinate our expertise. Between Cancer Services and these units in our Local Health District, we have recruited over 450 brain tumour patients and carers into clinical trials over the past 5 years.

One of my other main research interests is cancer survivorship, especially the late effects of cancer treatment and cognitive sequalae. People tend to think of the topic of "survivorship" as only relating to those who have a lengthy treatment journey, but, on the contrary, it is a theme which remains highly relevant to survivors of brain tumours. Our collective goal is that they can experience optimal quality of life with treatment sequelae minimised, for the duration of their lifespan.

What is a typical workday for you?

My workday commences whenever my four year old son decides to wake me up, usually between 6-630am. I am 'left-brain dominant' so sometimes I find creating a preschool 'art and craft extravaganza' more stressful than managing people with brain tumours!

The workday is a mixture of outpatient clinics, inpatient reviews, MDT meetings, and progressing research initiatives on a variety of fronts. Then in the evenings it's back on the home front, and ongoing - it's the typical juggling act of any working parent.

(continues on page 3)

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS

(continued from page 2)

How do you stay motivated to continue in your role? I am spurred on by the motivation and dedication of the healthcare professionals I work with. The courage and resilience of patients and carers is a great motivator. It always amazes me how families can still find the time to send you a lovely thank-you card amidst their time of grief and loss.

In late 2015, I lost my mother to breast cancer. Through the experience of journeying with her, especially through the palliative phase, it certainly gave me a firsthand knowledge of the significant burden of care carried by families. It must then be *even more so* for carers of those affected by brain tumours, who are often affected by loss in so many spheres of their life. These sorts of experiences serve as a constant reminder that there is much more to achieve in neuro-oncology, in terms of improving treatment outcomes through clinical trials. Whilst we all yearn for the significant "gamechanging" treatment or clinical trial in glioma, we can still oversee incremental improvements in all aspects of clinical care - areas that we can action THIS calendar year.

What are you looking forward to in 2016-7?

A definite highlight on our professional calendar will be COGNO hosting the ASNO (Asian Society for Neuro-Oncology) ASM in Sydney in September 2016. I look forward to seeing COGNO continue to makes its mark and for COGNO to be seen as a strong international clinical trials collaborator.

2015 COGNO/BRISTOL-MYERS SQUIBB YOUNG INVESTIGATOR AWARD REPORT



The Award was presented at the 2015 ASM to Dr Katrina Morris for her poster presentation on "Bevacizumab in Neurofibromatosis type 2 (NF2) related vestibular schwannomas: a UK nationally coordinated approach to delivery and prospective evaluation". Katrina's report appears below.

COGNO will again be providing a Young Investigator Award at the ASNO-COGNO Scientific Meeting 2016. The call for abstracts is now open - refer to page 7 and www.asnocogno2016.org.au/ for further details.

I would like to thank COGNO for their recognition of my work presented at the Annual Scientific Meeting in Brisbane in October 2015. This research was performed as part of my fellowship with the Neurofibromatosis type 2 (NF2) national specialty MDT service while based in Oxford, one of the 4 lead centres for the service which is responsible for monitoring the outcomes of the bevacizumab treatment program. It is the fruit of collaboration between the centres that make up the service and care for >90% of people with NF2 in England.

NF2 patients develop multiple nervous system tumours including bilateral vestibular schwannomas (VS). The tumours and their surgical treatment are associated with deafness, neurological disability, and mortality. Medical treatment with bevacizumab has been reported to reduce VS growth and to improve hearing and was introduced for NF2 patients with rapidly growing schwannoma in the UK in 2010 via the specialty service according to a predetermined protocol. Our study also aimed not only to assess volumetric and hearing outcomes but to determine other important consequences of treatment including patient-reported quality of life and the impact of treatment on surgical VS rates.

The first 61 patients treated with bevacizumab for rapidly growing schwannoma underwent serial prospective monitoring. This included MRI, audiology, clinical, CTCAE-4.0 adverse event recording, and NFTI-QOL quality-of-life assessments (a disease specific QOL measure). Tumour volumetric measurements were performed and classified according to the REiNs criteria (>20% change from baseline) and annual VS surgical rates reviewed. Of the 61 patients 59% were male, median age 25 years (range, 10-57), Median follow-up was 23 months (range, 3-53). Partial volumetric tumour response (all tumours) was seen in 39% and 51% had stabilization of previously growing tumours. Age and pretreatment growth rate were intercorrelated predictors of response. Younger patients (<18 years of age) having faster growing tumours and lower response rates. Hearing was maintained or improved in 86% of assessable patients. Mean NFTI-QOL scores improved from 12.0 to 10.7 (P < .05). Hypertension was observed in 30% and proteinuria in 16%. Twelve treatment breaks occurred due to adverse events. The rates of VS surgery decreased after the introduction of bevacizumab.

In conclusion, treatment with bevacizumab in this large, UK-wide cohort decreased VS growth rates and improved hearing and quality of life. The potential risk of surgical iatrogenic damage was also reduced due to an associated reduction in VS surgical rates. Ongoing follow-up of this cohort will determine the long-term benefits and risks of bevacizumab treatment.

Detailed results from this work are now published online in Neuro-Oncology Practice (Morris KA, Golding JF, Axon PR, Afridi S, Blesing C, Ferner RE, Halliday D, Jena R, Pretorius PM, Evans DG, McCabe MG, Parry A (2016) Bevacizumab in Neurofibromatosis type 2 (NF2) related vestibular schwannomas: a nationally coordinated approach to delivery and prospective evaluation. Neuro-Oncology Practice In press:npv065. doi:10.1093/nop/npv065).

STUDY & TRIAL UPDATES

CATNON (EORTC 26053-22054): Phase III trial on concurrent and adjuvant Temozolomide chemotherapy in non-1p/19q deleted anaplastic glioma

The recruitment for the CATNON study closed on 17 September 2015 with 751 patients randomised internationally (1407 registered), and 82 randomised in Australia (191 registered); this represents approximately 11% of total trial accrual and is a great contribution to the global effort.

The EORTC is conducting an interim analysis for 31 March 2016 with cut-off date 31 May 2015. Our Australian sites continue to work hard to ensure that all of the patient information is provided to the EORTC for this important analysis and their efforts are, as always, very much appreciated.

A CATNON abstract (with authors including Anna Nowak and Helen Wheeler) has been accepted for an oral presentation at ASCO in June.

The CATNON Trial Coordinator is happy to provide any information that you may require and can be reached by emailing any questions or requests to <u>catnon@ctc.usyd.edu.au</u>.

VERTU (COGNO 14/01): <u>VE</u>liparib, <u>R</u>adiotherapy and <u>T</u>emozolomide trial in <u>U</u>nmethylated 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 methyltransferase (MGMT).

Following the start of recruitment on 28 October 2015, the study has now registered 28 and recruited 6 patients. 9 sites have opened to recruitment and another 4 are expected to be opened in the next few weeks. As VERTU was successful in obtaining additional funding, the study will also be opening additional sites.

A number of protocol changes were identified to improve the trial conduct, particularly with regards to collection of tissue for screening and translational research, and with regards to scheduling screening and baseline assessments. A protocol amendment was submitted to the ethics committee on 10 February 2016. The team is currently awaiting feedback from the committee.

The VERTU Trial Coordinator is more than happy to provide any information that you may require on this study. Please email <u>vertu@ctc.usyd.edu.au</u> if you have any queries.

VERTU - PARTICIPATING SITE STATUS PER 01-MAR-2016								
No	Site name	State	Principal Investigator	Site status	Site activation	# Patients registered	# Patients enrolled	
1	Royal North Shore Hospital	NSW	Helen Wheeler	Active	09-Nov-15	8	1	
2	Chris O'Brien Lifehouse	NSW	John Simes	Active	26-Nov-15	3	0	
3	Liverpool Hospital	NSW	Eng-Siew Koh	Active	21-Jan-16	1	0	
4	Gosford Hospital	NSW	Matthew Wong	Not active	Apr-16	0	0	
5	Royal Melbourne Hospital	VIC	Mark Rosenthal	Active	28-Oct-15	2	1	
6	University Hospital Geelong	VIC	David Ashley	Active	21-Jan-16	1	0	
7	Epworth Healthcare	VIC	Ross Jennens	Active	14-Dec-15	1	0	
8	Monash Medical Centre	VIC	Ronnie Freilich	Active	11-Feb-16	0	0	
9	Royal Brisbane and Women's Hospital	QLD	Zarnie Lwin	Active	09-Nov-15	9	3	
10	Princess Alexandra Hospital	QLD	Matthew Foote	Not active	Apr-16	0	0	
11	Royal Adelaide Hospital	SA	Nimit Singhal	Not active	Mar-16	0	0	
12	Sir Charles Gairdner Hospital	WA	Anna Nowak	Not active	Mar-16	0	0	
13	Royal Hobart Hospital	TAS	Rosemary Harrup	Active	02-Dec-15	3	1	



MANAGEMENT COMMITTEE

Prof Mark Rosenthal (Chair) Prof John Simes (Deputy Chair) Dr Liz Hovey (Treasurer) Dr Eng-Siew Koh (Secretary) Prof Meera Agar A/Prof Kate Drummond Ms Marcia Fleet A/Prof Matthew Foote Prof Terry Johns Ms Robyn Leonard

SCIENTIFIC ADVISORY COMMITTEE

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OPERATIONS EXECUTIVE COMMITTEE

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NEW CONCEPTS/TRIALS IN DEVELOPMENT

ACED (COGNO14/02): Phase II randomised placebo-controlled, double blind, multisite study of acetazolamide versus placebo for management of cerebral oedema in recurrent and/or progressive HGG requiring treatment with dexamethasone - the ACED trial.

The ACED study aims to recruit 84 patients across 3-12 sites. While preparing for start of recruitment some important changes were identified to the protocol. Therefore a protocol amendment was submitted to the Ethics Committee on 15 February 2016. The team is currently awaiting feedback from the committee.

Meanwhile the first three sites - Liverpool Hospital (NSW), Royal Brisbane and Women's Hospital (QLD) and St. Vincent's Hospital Melbourne (VIC) - have completed their local ethics and governance review and will be ready to kick-off the study at their hospital, once the amendment has been approved at their site. The study team continues working diligently to prepare all study documents, systems and procedures to facilitate an efficient conduct of the trial.

It is anticipated this study will commence recruitment end of the first quarter, or early in the second quarter of 2016. Please email <u>aced@ctc.usyd.edu.au</u> if you have any queries.

DO YOU HAVE A NEW TRIAL CONCEPT? COGNO is always looking to develop new trials - from inception through to full protocol development and managing feasibility and operational issues. We aim to help progress and support development of important clinical trial questions. If you would like to propose a concept or have an amazing idea for a COGNO trial, please contact us on cogno@ctc.usyd.edu.au or call Kate Sawkins (COGNO Development Program Manager) on 02 9562 5374. Kate and the team can assist you to develop and progress your idea or assist you with completion of the Trial Concept Outline form available at www.cogno.org.au (on the home page under 'Ideas and Concepts'). See also below re our Ideas Generation Workshop.

The COGNO team has been busy preparing three grant applications for NHMRC/Cancer Australia/Cancer Council funding, which have now been submitted. We expect to receive initial feedback in June/July with final confirmation of the outcome of the applications in December.

COGNO IDEAS GENERATION WORKSHOP

COGNO will be holding an Ideas Generation Workshop on Monday 23 May 2016, in Sydney. The workshop will be targeted at identifying areas of unmet need in relation to neuro-oncology clinical trials in Australia and globally. If you are interested in participating and have ideas relating to gaps in current knowledge, or ideas for future clinical trials in neuro-oncology we would like to hear from you. Please send up to 1 paragraph outlining your ideas to <u>cogno@ctc.usyd.edu.au</u> by **5pm on Friday 29 April 2016**.

Submissions are welcome from all disciplines, and at any stage of development. If you would like to discuss your idea prior to submission please feel free to contact Kate Sawkins (COGNO Development Program Manager) at <u>kate.sawkins@ctc.usyd.edu.au</u> or on (02) 9562 5374.

MEMBERSHIP UPDATE

COGNO now has 470 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 (<u>www.cogno.org.au</u>) or office (<u>cogno@ctc.usyd.edu.au</u>).

COGNO TEAM UPDATE

Since our last newsletter we've had a number of farewells and welcomes. We farewell Renee Swanson (COGNO's Associate Oncology Program Manager - Development), Elise Robertson (CATNON and CABARET trial coordinator) and Felicia Roncolato who has completed her term as COGNO's Research Fellow. Renee is relocating to Newcastle and we will miss her greatly, thank you Renee for all your hard work. We wish Elise all the best in her studies in her new chosen career of high school teaching, and Felicia all the best in her future endeavours.



We welcome Jaclyn Verghis who is joining the COGNO team as the trial coordinator on the ACED trial. Jaclyn has been working as a trial coordinator at the CTC for the past two years, primarily on the international TOPGEAR trial of gastric cancer. Her clinical research interests began in her prior role at Memorial Sloan Kettering Cancer Center in New York in a research role focusing on lower GI cancer research. Jaclyn is currently enrolled in a Masters degree in Nursing, at the University of Sydney, part-time, and for fun and balance, she bikes and practices yoga, and enjoys travelling when she can.

We also welcome back Kate Sawkins, Di Winter and Joe Levitt. Kate and Di are both returning from maternity leave (Kate as COGNO's Development Program Manager and Di as CABARET trial coordinator) and we are lucky to have Joe working for COGNO once again as CATNON trial coordinator.

OPTIMAL CARE PATHWAY FOR PEOPLE WITH HIGH GRADE GLIOMA

To help people diagnosed with cancer receive the best possible care, the *Optimal care pathway for people with high grade glioma* has been developed by the Cancer Council Victoria on behalf of the Victorian Department of Health and Human Services.

The clinical guides for health professionals set out key principles for optimal care at each step of the patient journey from prevention through to survivorship / end of life care. The guide has been endorsed by the Australian Health Ministers Advisory Council (AHMAC), National Cancer Expert Reference Group (NCERG), Cancer Australia and Cancer Council Australia - enabling centralised structural support for implementation across Australia. View the *Optimal care pathway for people with high grade glioma* at www.cancer.org.au/OCP.

Patients and their family and carers can use the consumer version to better understand an often complex health system, and to know what questions to ask of their health professionals to ensure they receive the best care at every step. Help your patients and their family and carers understand the process they are going through by printing and sharing these guides as appropriate. View the interactive consumer web portal or download the *high grade glioma - what to expect* PDF at www.cancerpathways.org.au.

REMINDERS/ADDITIONAL INFORMATION

- 29 April 3 May 2016 ESTRO, Lingotto Fiere, Turin, Italy <u>http://</u> www.estro.org/congresses-meetings/items/estro-35
- 3-7 June 2016 ASCO, McCormick Place, Chicago, USA http://am.asco.org/
- 11-15 September 2016 ASNO-COGNO Scientific Meeting 2016, Sheraton on the Park, Sydney, Australia www.asnocogno2016.org.au
- 15-17 November 2016 COSA/ANZBCTG ASM, Gold Coast Convention and Exhibition Centre, Australia <u>http://cosa2016.org/</u>
- 17-20 November 2016 SNO, Fairmont Scottsdale Princess, Scottsdale, USA http://www.soc-neuro-onc.org/



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The ASNO-COGNO Scientific Meeting 2016 website is now live at www.asnocogno2016.org.au.

Calling for Abstracts!

Abstract submissions are now open. Members of the neuro-oncology community and related professionals are invited to submit abstracts for presentation as part of the ASNO-COGNO Scientific Meeting 2016. Abstracts for both poster and oral presentations including original work in clinical, translational and allied health research will be considered. The submission closing date is Sunday 1 May 2016. More details available at www.asnocogno2016.org.au/abstract-submission.

Three prize awards are available in relation to abstracts: Young Investigator Award, Most Outstanding Oral Presentation and Most Outstanding Poster Presentation. More detail available on www.asnocogno2016.org.au/grants-awards.

For more information or to register for updates visit www.asnocogno2016.org.au



ASNO-COGNO Scientific Meeting 2016 CONFIRMED INTERNATIONAL SPEAKERS



PROF ROGER STUPP MD



PROF MITCH BERGER MD FACS FAANS



PROF PAUL MISCHEL MD



ASSOC PROF ARJUN SAHGAL BSC, MD, FRCPC



PROF W. K. ALFRED YUNG MD



PROF GREGORY RIGGINS MD PHD



ASST ADJ PROF MARY LOVELY PHD, RN, CNRN (Courtesy of Brain Tumour Alliance

Australia)





COOPERATIVE TRIALS GROUP FOR NEURO-ONCOLOGY

The achievement of better health outcomes for patients and those affected by brain tumours through clinical trials research