

Quick Update:

- Membership: 428 members
- 8th COGNO ASM Save the Date! 23rd-24th Oct, Brisbane



COGNO

COOPERATIVE TRIALS GROUP
FOR NEURO-ONCOLOGY

Member Newsletter

Issue 18

Autumn 2015



Message from our Chair

Welcome to another COGNO newsletter.

At nearly eight years of age, COGNO has established an international reputation, provides a nexus for neuro-oncology clinical trials in Australia, and more importantly, has established itself as the forum for all those interested in neuro-oncology clinical research including trials. We have a large membership base representing many craft groups and a very active Scientific Advisory Committee.

The CABARET study has achieved international prominence and I am thrilled to report that Liz Hovey has been selected, on behalf of COGNO, to give an oral presentation at ASCO in June. This is a wonderful achievement for the entire CABARET team and in particular Liz and the Principal Investigator, Kathryn Field. We continue to contribute significantly to the CATNON study and this has raised our international profile. Our current trial portfolio has two new trials commencing (see page3) and there are a number of potential studies coming our way.

The Executive is committed to the success of COGNO but recognises that new ideas and new people are essential. First, I wish to thank and congratulate Mustafa Khasraw and Zarnie Lwin in running their second and very successful Ideas Generation Workshop. Secondly, many of your senior clinicians have made arduous international trips to be present at important meetings of our international counterparts such as the EORTC, NCIC and the USA Cooperative groups. These trips are to ensure we have a foot in the door when new studies are discussed. Finally, the Executive understands that it is critical to review strategy and improve on what we do. So with that in mind, COGNO will be conducting its second strategic review in June: a time to reflect on what has worked well and what we need to do to ensure the ongoing success of COGNO.

I encourage you all to attend the 2015 ASM in Brisbane. The COGNO ASMs have been terrific meetings and I'm sure that this will be no exception with some outstanding international guests and a strong line-up of national experts.

Finally, a new addition to the newsletter: "Getting to Know You". And so appropriate to start with Robyn Leonard, one of our longest serving Management Committee members, and our consumer representative who has played an integral role in COGNO's success.

Mark Rosenthal
Group Chair

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8th COGNO ASM - 'WHERE THE FUTURE LIES'

Friday 23rd - Saturday 24th October 2015

Brisbane, Australia

Dr Cecelia Gzell, 2015 ASM Convenor, and the organising committee are hard at work developing an interesting and topical scientific program. Confirmed international speakers are Professor Martin J van den Bent, Professor Kenneth D Aldape and Professor Vinay Puduvalli. SAVE THE DATE and check out the ASM website following its launch on 1 May 2015.

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS



Ms Robyn Leonard is the consumer representative member on the COGNO Management Committee, as well as the COGNO Scientific Advisory Committee. Robyn has been immersed in the brain tumour community since her daughter Lucie was diagnosed with a grade 3 astrocytoma in 2006. An almost seven year survivor, Lucie passed away in November 2012.

Over almost a decade, Robyn has dedicated herself to improving awareness, support and treatment for people with brain cancer, and last year established Australia's first brain cancer biobanking consortium to network and streamline tissue-banking operations and support researchers with high-quality tissue and data.

How did you make the transition from carer to consumer advocate?

Initially I just wanted to help Lucie and I made it my business to find the best information and people for her treatment. At times that was really quite difficult and the support I thought should be available wasn't. It seemed selfish not to use the information I gathered to help other people and fight for better treatments and care.

What is the greatest challenge of being a consumer representative?

It's very difficult to keep reliving the events of Lucie's cancer experience. Her youth, the tumour's progression, remission and recurrence, treatments and side effects, and our own clinical trial experience in the US (DCVax trial at UCLA). I have to draw on my experience and try to imagine how I would feel if this was Lucie.

What is your role on the COGNO Management and Scientific Advisory Committees?

It's my responsibility to provide input from a consumer's perspective at all stages of the development and implementation of brain cancer clinical trials - as well as the dissemination of information on the results of those trials to the general brain cancer community.

During your time with COGNO you initiated the establishment of a network to provide support and resources for all consumer representatives on national cooperative trials groups. Why was this important?

I found there was a lot of training and resources for consumer representation on general groups, but nothing to support worthwhile consumer contribution to such highly scientific committees, where you are reviewing clinical trials documentation, in many instances as the only 'lay' person in the Group. By establishing the Cancer Trials Consumer Network (CTCN), we have unified consumer advisors of 14 National Cancer Cooperative Trials Groups to share knowledge, ideas, and resources, provide support and assist with consumer training and mentoring.

How did your interest in biobanking eventuate?

I understood that biobanking was fundamental to research through my association with COGNO, but it was through my involvement with AGOG (Australian Genomics and Clinical Outcomes of Glioma) that I realised it needed to be coordinated on a national level.

I was supported by COGNO to attend the International Society for Biological and Environmental Repositories (ISBER) annual conference in Sydney in 2013 and that's where my interest was really fired up.

The light bulb moment came at a session where I heard about a consumer advocate in the US who has established biobanks and biobanking networks for rare and under-researched diseases. Obvious next thought...if she can do it maybe I can too!

What is the National Brain Cancer Biobanking Consortium (NBCBC)?

The NBCBC is a group of leading brain cancer clinicians, researchers and biobankers who have joined forces to drive research through the streamlining of brain cancer biobanking operations Australia-wide. We want to provide researchers easy access to the amount, quality and type of tissue (and associated data) they need to make progress.

The Consortium operates under the umbrella of COGNO, creating the unique opportunity to enhance translational research by taking pre-clinical research projects into clinical trials and on to much needed treatments for brain cancer patients.

A simple idea that I hope is going to make a big difference.

How do you stay motivated to continue in your role?

My motivation comes from a comment Lucie made when I wanted to stop. Her response was "you can't do that" and I thought "well I can't now"! I knew my involvement meant a lot to her. She understood better than anyone how the lack of survivors and devastating impact of the disease equals a lack of advocates.

I am also motivated by the many committed individuals and organisations that have supported me to initiate or be involved in so many worthwhile projects.

What are three changes you want to achieve through your work?

1. It would be wonderful if tissue from every patient who has an operation for brain cancer in Australia could be biobanked.
2. To ensure that every tissue specimen donated is used for maximum scientific and health benefit.
3. To see consortium research projects translated into clinical trials and on to improvements in patient care.

If you would like to know more about the NBCBC, please contact Project Coordinator, Mythily Mariasegaram, on mythily.mariasegaram@ctc.usyd.edu.au.

STUDY & TRIAL UPDATES

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

The CATNON study has now randomised 692/748 patients internationally and has registered 1311 patients. 77 patients have been randomised and 171 patients have been registered in Australia alone.

We recently received a trial status update from the EORTC Project Manager thanking us for our contribution and commitment to the CATNON trial to date. There are now less than 60 patients required to join the trial to reach the required accrual goal.

As always, the CATNON Trial Coordinator, Lisa Bailey welcomes all suggestions and queries and is happy to provide any assistance required. Please email catnon@ctc.usyd.edu.au if you have any questions.

CATNON Recruitment by Site							
No	Site name	State	Principal Investigator	Date activated	No. of patients registered	No. of patients deemed ineligible	No. of patients randomised
1	Royal North Shore Hospital	NSW	Helen Wheeler	20-Aug-10	41	21	20
2	Royal Hobart Hospital	TAS	Rosie Harrup	8-Sep-10	11	4	7
3	Austin Health	VIC	Lawrence Cher	21-Jun-10	13	11	2
4	Sir Charles Gairdner Hospital	WA	Anna Nowak	29-Sep-10	20	10	10
5	The Alfred	VIC	Sanjeev Gill	31-Aug-11	27	12	13
6	St. Vincent's Hospital Melbourne	VIC	Anthony Dowling	22-Mar-11	19	9	9
7	Royal Melbourne Hospital	VIC	Mark Rosenthal	3-Sep-10	14	9	6
8	Flinders Medical Centre	SA	Ganessan Kichenadasse	26-Jul-11	7	5	2
9	Royal Prince Alfred Hospital/Chris O'Brien Lifehouse	NSW	John Simes	11-Mar-11	5	1	3
10	Princess Alexandra Hospital	QLD	Katharine Cuff	14-Dec-11	6	4	2
11	Westmead Hospital	NSW	Najmun Nahar	23-Jul-13	4	3	1
12	Prince of Wales Hospital	NSW	Elizabeth Hovey	30-Oct-13	0	0	0
13	Royal Brisbane and Women's Hospital	QLD	Po Ling-Inglis	7-May-14	4	2	2
Current at 4 Mar 2015				Total	171	91	77

NEW CONCEPTS/TRIALS IN DEVELOPMENT

COGNO is very excited to announce 2 trials currently in development and due to open in 2015.

VERTU: 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). This study will recruit 120 participants with newly diagnosed patients with histologically confirmed GBM (WHO grade IV) following surgery, with unmethylated MGMT promoter gene GBM. This study now has central ethics approval and the CTC team will be in contact with sites in the near future to commence site start up and local governance documentation. It is anticipated this study will start mid-2015.

ACED: 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. This study will recruit 84 participants with GBM, HGG, AA, AO (progressive and/or recurrent disease) who require dexamethasone recommencement or dose increase due to progressive raised ICP. The central ethics application was submitted in November. It is anticipated this study will start in mid-2015. Feasibility surveys have been completed and final site selection will occur in the near future.

MEMBERSHIP UPDATE

COGNO'S membership continues to increase with numbers now at 428. 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).

IDEAS GENERATION WORKSHOP 2015

COGNO held its second Ideas Generation Workshop on 27 March 2015 in Sydney, co-chaired by Dr Mustafa Khasraw and Dr Zarnie Lwin. A number of interesting ideas and concepts were discussed, and it is anticipated that some will be able to be further developed and submitted for further review and consideration by the COGNO Scientific Advisory Committee (SAC).

MANAGEMENT COMMITTEE

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



Co-chairs Dr Mustafa Khasraw
and Dr Zarnie Lwin

SCIENTIFIC ADVISORY COMMITTEE

Dr Liz Hovey (Chair)
 Dr Eng-Siew Koh (Deputy Chair)
 A/Prof Meera Agar
 Ms Liz Barnes
 A/Prof Kate Drummond
 Dr Matthew Foote
 Dr Lindy Jeffree
 Prof Terry Johns
 Ms Marina Kastelan
 Dr Danette Langbecker
 Ms Robyn Leonard
 Mrs Ann Livingstone
 Dr Kerrie McDonald
 Dr Anna Nowak
 Prof Mark Rosenthal
 Dr Gail Ryan
 Prof John Simes
 Dr Helen Wheeler

Ms Marina Kastelan and
Prof John Simes



DO YOU HAVE A NEW CONCEPT? COGNO is always looking to develop new studies - 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 clinical trial, please contact us on cogno@ctc.usyd.edu.au or call and chat to Renee Swanson, Associate Oncology Program Manager, on 02 9562 5374. The SAC meets quarterly and Renee 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.

CHERE/CREST

The Cancer Research Economics Support Team (CREST) has been set up at the Centre for Health Economics Research and Evaluation (CHERE) within the University of Technology, Sydney, as part of the Cancer Australia Support for Clinical Trials program and the Boost Cancer Research Measure. CREST has produced the following additions to their ongoing FactSheet series:

- Translating Clinical Trial Data for use in an Economic Evaluations
- Discounting in Economic Evaluations in Health Care: A Brief Review

These (and others in the FactSheet series) are available at <http://www.crest.uts.edu.au/resources/documents.html>

REMINDERS

- 3-9 May 2015 - Brain Cancer Action Week, <http://www.btaa.org.au/events>
 - 8 May 2015 - Sydney Patient Education & Support Forum, <http://www.btaa.org.au/events/3/brain-cancer-action-week-sydney>
 - 8 May 2015 - Melbourne Community Information & Education Program, <http://www.btaa.org.au/events/7/brain-cancer-action-week-melbourne->
- 29 May - 2 June 2015 - ASCO, McCormick Place, USA, <http://am.asco.org/>
- 17-20 Sept 2015 - ASNO, Manila, Philippines, <http://www.asno2015.com/>
- 7-10 October 2015 - ACTA, Sydney, Australia, <http://www.acta2015.com.au/>
- 23-24 October 2015 - 8th COGNO ASM, Brisbane, Australia, <http://www.cogno.org.au/>

COGNO Team Update

We farewell Hannah O'Riley (and wish her all the best for the completion of her PhD) and Kate Sawkins (who is on maternity leave with new baby Darcy - congratulations Kate!). We also welcome a number of new staff members to COGNO.



Merryn Hall joins the COGNO trials team as Associate Oncology Program Manager, with responsibility for the operational management of COGNO trials. Merryn is coming up to her 10th year with the NHMRC Clinical Trials Centre and has worked on numerous trials with local and international collaborators through the Australasian Gastro-Intestinal Trials Group (AGITG) clinical trial network. She has had experience in investigator-initiated data trials as well as larger international trials in medical oncology, surgical and radiation therapy. Prior to 2005, Merryn worked at a site level as a trial coordinator on several cardiology and anaesthetics clinical trials. She also oversees Operations Management for the Australasian Lung cancer Trials Group (ALTG) trials group and works 3 days a week (Monday-Wednesday).



Renee Swanson joins the COGNO trials team as Associate Oncology Program Manager, with responsibility for trials development. After growing up in Newcastle and completing a B.Sc. Biotechnology (Hons) degree at the University of Newcastle, Renee continued her honours project as a Research Assistant at the Hunter Medical Research Institute in 2002. Renee then decided to broaden her horizons and move to Sydney where she has undertaken various clinical research roles: Study Coordinator and Clinical Trial Manager at the Woolcock Institute of Medical Research (2003-2007), Clinical Operations Manager and most recently Operations Manager (Biological Sciences and Clinical Research) at the Brien Holden Vision Institute (2007-2014). Renee's experience covers several therapeutic areas including: Endocrinology/Neonatology, Respiratory, Sleep, and Optometry (Medical Device trials) and is now looking forward to working on a part-time basis with the COGNO team developing new concepts which translate into clinical trials. In Renee's spare time she enjoys spending time with her family and going to the gym.



Dave Cannan started at the NHMRC Clinical Trials Centre in July 2011 where he started on AGITG & ANZGOG trials. Dave joined the COGNO team in January 2015 as CABARET Trial Coordinator and assists with other COGNO trials such as CATNON. He has Bachelor of Science (Biological Sciences) from LaTrobe University in Victoria and has previously worked for Commonwealth Serum Laboratories (CSL), Murdoch Children's Research Institute (MCRI) and the Mount Sinai School of Medicine in New York. Dave is already a father of one child and will be expecting his second in September.



Martijn Oostendorp joined the NHMRC Clinical Trials Centre and the COGNO group shortly after his relocation from The Netherlands earlier this year. Martijn has a Master's degree in Biology from the University of Nijmegen, The Netherlands. In the past 11 years he worked for several pharmaceutical, CRO (contract research organisation) and ARO (academic research organisation) companies including Julius Clinical, an ARO, where he led the data management department and worked as lead data manager and on multiple international clinical trials. Martijn will be the Trial Coordinator for the upcoming COGNO trials ACED and VERTU. Outside the office you may find him bushwalking, travelling, practising taekwondo, or enjoying the good company of friends over a nice dinner or beer.



Mythily Mariasegaram recently commenced as the part-time Project Coordinator for the National Brain Cancer Biobanking Consortium (NBCBC) which operates under the umbrella of COGNO. Originally from Melbourne, Mythily completed a PhD in medical research at Monash University and worked as a research fellow for a few years before moving to Brisbane. While in Brisbane Mythily worked in a breast cancer tissue bank at the University of Queensland before relocating to Sydney to work for the Australian Breast Cancer Tissue Bank, where she continues to work on the days she is not working for the NBCBC.



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