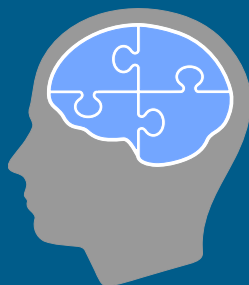


Quick Update:

- Membership: 479 members
- ASNO-COGNO Scientific Meeting 2016 update

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COGNO

COOPERATIVE TRIALS GROUP
FOR NEURO-ONCOLOGY

Member Newsletter

Issue 22

Winter 2016

Message from our Chair



Dear COGNO members,

Welcome to the winter edition of the COGNO newsletter. COGNO remains an active and energetic organisation and the newsletter provides some insights for our members. Most effort is focussed on the rapidly approaching ASNO-COGNO Scientific meeting to held in Sydney from Sunday 11th to Wed 14th of September. Liz Hovey and Cecilia Gzell are the Convenors working with a multidisciplinary Organising Committee. I'm particularly appreciative of the work undertaken by our star duo: Zarnie Lwin and Mustafa Khasraw who are responsible for the program itself. I sincerely hope that all COGNO members consider attending as I know it will be an outstanding meeting with something for everyone.

This newsletter chats to Marcia Fleet in our 'getting to know you' series and also details where things currently stand with a number of clinical trials. I was delighted to see COGNO and our Investigators, particularly Helen Wheeler and Anna Nowak, recognised internationally when the CATNON study was presented at the recent American Society of Clinical Oncology meeting: in the Plenary Session no less. Our third Ideas Generation Workshop was held in May and the outcomes are noted here.

One other item is worth noting in my Chairman's report. All COGNO full members had the opportunity to participate in our on-line Strategic Direction Survey. This was in line with one of the recommendations from our Strategic Planning Day in June 2015. At that meeting, despite the remarkable membership numbers, the degree of membership engagement was questioned. The results of this survey were circulated to members in May 2016 and affirmed the thoughts of the Management Committee. The COGNO Executive is developing strategies to address the issues raised in the survey and the Strategic Planning Day, and I will keep you updated.

Mark Rosenthal
Group Chair

**13TH ASIAN SOCIETY FOR NEURO-ONCOLOGY (ASNO) MEETING /
9TH COGNO ANNUAL SCIENTIFIC MEETING**
"Neuro-Oncology: is the landscape changing?"
Sunday 11th - Wednesday 14th September 2016, Sheraton on the Park, Sydney, Australia

Registration for the ASNO-COGNO Scientific Meeting 2016 is now open at www.asnocogno2016.org.au/registration/. Early bird closes **Monday 11 July 2016**, so register now to secure your spot at the discounted early bird rate!

(continues on page 2)

ASNO-COGNO SCIENTIFIC MEETING 2016

(continued from page 1)

The Organising Committee has secured an incredible line up of keynote and invited [speakers](#) and will host a comprehensive [program](#) to interest all individuals in the Neuro-Oncology field. On Sunday 11 September we will also host two [workshops](#):

- **SRS Workshop (Cranial Stereotactic Radiosurgery):** An interactive and information workshop on cranial stereotactic radiosurgery for beginners and experts alike.
- **Glioma Master Class:** The Glioma Master Class offers a unique opportunity for clinicians, trainees and non-clinicians to hear how our panel of acclaimed international and national speakers care for their patients: "How I do it".

A half day consumers forum will be held on the morning of Tuesday 13 September 2016. Further details, when available, will be on the BTAA and ASNO-COGNO Scientific Meeting 2016 websites.

BTAA Educational Grants for Allied Health Professionals/Researchers to attend the ASNO-COGNO Scientific Meeting 2016: The BTAA grants are up to \$600, to assist with travel/accommodation. The grants are open to Allied Health Professionals/researchers who are BTAA members and are not supported by other grants. Membership of BTAA is a \$20 joining fee and \$10 a year. More information about the education grants is available at <https://www.btaa.org.au/news/77/btaa-educational-grants->.

ASNO
13th Asian Society for Neuro-Oncology (ASNO) Meeting /
9th COGNO Annual Scientific Meeting
11-14th September 2016
Sydney, Australia
Neuro-Oncology: is the landscape changing?
Photo by Jonathon Marks, Tourism Australia

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS



Ms Marcia Fleet is on the COGNO Management Committee and has been on the ASM organising committees for 2013 & 2014. Marcia is a radiation therapist turned care coordinator in the Neuro-Oncology Unit at Royal Melbourne Hospital.

How did you become involved in COGNO?

I have always been someone who believes you should be involved in groups that relate to the area you work in. As a radiation therapist I was very involved in the professional body and other activities around that professional group. When I made the transfer to care coordination I believed I needed to be involved to learn about the area I was now working in. I attended the COSA conference in 2009 on the Gold Coast and the following year started to attend the COGNO ASM. A year or two later I was asked to join the management committee as the non-medical/non research representative. When you work with Mark Rosenthal and Kate Drummond you can't help but be enthused and involved.

Why are you still a COGNO member?

I like the inclusiveness of COGNO. It covers all craft groups and no area feels less than any of the other groups. There is a consumer input into activities and any of the trials undertaken. New or inexperienced investigators are mentored through the process of developing a trial protocol and helped to try and get their idea to 'grow legs'. I still am involved because it provides me with the understanding of the direction neuro-oncology is heading. The ASMs always have excellent overseas and local speakers who are prepared to share their knowledge and expertise with the attendees.

Why did you become a care coordinator?

I had trained many years ago as a radiation therapist (in fact when radiation oncologists gave the chemotherapy)! I had worked in both Victoria and NSW in the public sector and in Victoria in the private sector. I also worked for the professional body on contract for 3 ½ years as a project manager managing a multimillion dollar project of Federal Government funding for radiation therapists.

(continues on page 3)

GETTING TO KNOW COGNO'S MANAGEMENT COMMITTEE MEMBERS

(continued from page 2)

At the end of that I looked at other areas I could work in using my skills I had developed from many years in the oncology field. A project came up at RMH to look at whether care coordinators needed to be nurses or not. The outcome of the project was no and consequently I was given permanent employment as the neuro-oncology and colorectal oncology care coordinator. It has been an extremely rewarding position, working in a wonderful team and using my skills from many years in oncology.

What do you find challenging about you work, and most rewarding?

The most challenging is being with the patient and family after they have been given a diagnosis and then trying to work through the next while with them and where they are heading. This same challenge occurs when they are told that there is no further active treatment that can be offered to them other than best supportive care. The rewarding part of the job is the relationship that you develop particularly with the carers.

What is a typical day for you?

My day varies with what comes along and needs to be dealt with.

There are some days that are set. Monday starts with a ward audit then on to the neuro-oncology MDM, followed by clinic. In clinic I would speak to the patients and carers to check they are coping and OK, make sure they have their multiply appointments within the clinic. After clinic I coordinate the patient's ongoing appointments for investigations etc. I constantly answer patients and carers queries and requests for the medical staff to do things. I help with ward discharges and referrals to other oncology centres around the country. Make appointments and organising imaging for patients who have finished RT and require follow up in the clinic. I run a monthly support group for high grade patients and carers. I am involved in a neuro-oncology care coordinator's group in Victoria who with the CCV organise community days and webinars.

What do you do in your spare time?

I enjoy entertaining friends at home as well as eating out. Go to the football and cricket as well as theatre both play and musical theatre along with the Australian ballet. Each year I try to do an overseas trip and am gradually working my way through Europe. My life outside work is as busy as it is at work and as varied.

STUDY & TRIAL UPDATES

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 study aims to recruit 84 patients across 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. This has now been approved centrally and V2.0 dated 8 February 2016, has been sent to sites for local submissions.

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.

We are in the process of site selection for the additional sites. It is anticipated this study will commence recruitment in the second quarter of 2016. Please email aced@ctc.usyd.edu.au if you have any queries.

| ACED - PARTICIPATING SITE STATUS | | | | | | |
|----------------------------------|-------------------------------------|-------|------------------------|-----------------------|-----------------|-----------------------|
| No | Site name | State | Principal Investigator | Site status | Site activation | # Patients randomised |
| 1 | Liverpool Hospital | NSW | Eng-Siew Koh | Initiated | Pending | - |
| 2 | Royal Brisbane and Women's Hospital | QLD | Zarnie Lwin | Pending v2.0 approval | Pending | - |
| 3 | St Vincent's Hospital, Melbourne | VIC | Anthony Dowling | Pending v2.0 approval | Pending | - |
| Total recruitment | | | | | | 0 |

STUDY & TRIAL UPDATES

VERTU (COGNO 14/01): 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 methyltransferase (MGMT).

The VERTU Trial has now been open to recruitment for 7 months. Sites are actively looking for potential participants and new patients are being registered every week. As expected, there are quite some screen failures due to MGMT methylation and decline in performance status prior to randomisation. To ensure recruitment rates remain on target, all participating sites are requested to continue actively searching for patients that may be suitable to join the trial. An Investigator Teleconference is being scheduled in June to discuss recruitment strategies and best practices, and to share experiences from the first months of running the VERTU trial.

Most active sites have obtained approval for working under protocol version 2.0, or are well underway in preparation for protocol 2.0 implementation. The new version of the protocol, released in March 2016 to active sites, aims to improve the study logistics during the screening period. To further improve trial logistics, the VERTU electronic Case Report Form has been upgraded, using a newer version of the Electronic Data Capture System (InForm 6.0).

Our Study Chair, Dr Mustafa Khasraw and multiple participating Investigators will be attending the ASCO conference that is being held in Chicago, USA, from June 3rd until June 7th, 2016. The VERTU Trial's abstract and poster was accepted into the "Trial In Progress" category, emphasising its high relevance in the field of GBM.

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.

| VERTU - PARTICIPATING SITE STATUS | | | | | | | |
|-----------------------------------|-------------------------------------|-------|------------------------|-------------|-----------------|-----------------------|---------------------|
| No | Site name | State | Principal Investigator | Site status | Site activation | # Patients registered | # Patients enrolled |
| 1 | Canberra Hospital | ACT | Ganes Pranavan | Not active | TBC | - | - |
| 2 | Royal North Shore Hospital | NSW | Helen Wheeler | Active | 09-Nov-15 | 19 | 4 |
| 3 | Chris O'Brien Lifehouse | NSW | John Simes | Active | 26-Nov-15 | 7 | 2 |
| 4 | Liverpool Hospital | NSW | Eng-Siew Koh | Active | 21-Jan-16 | 3 | 0 |
| 5 | Gosford Hospital | NSW | Matthew Wong | Not active | Jun-16 | - | - |
| 6 | Royal Melbourne Hospital | VIC | Mark Rosenthal | Active | 28-Oct-15 | 2 | 1 |
| 7 | University Hospital Geelong | VIC | David Ashley | Active | 21-Jan-16 | 3 | 0 |
| 8 | Epworth Healthcare | VIC | Ross Jennens | Active | 14-Dec-15 | 2 | 0 |
| 9 | Monash Medical Centre | VIC | Ronnie Freilich | Active | 11-Feb-16 | 0 | 0 |
| 10 | Royal Brisbane and Women's Hospital | QLD | Zarnie Lwin | Active | 09-Nov-15 | 11 | 5 |
| 11 | Princess Alexandra Hospital | QLD | Matthew Foote | Not active | Jun-16 | - | - |
| 12 | Royal Adelaide Hospital | SA | Nimit Singhal | Active | Mar-16 | 2 | - |
| 13 | Sir Charles Gairdner Hospital | WA | Anna Nowak | Not active | TBC | - | - |
| 14 | Royal Hobart Hospital | TAS | Rosemary Harrup | Active | 02-Dec-15 | 4 | 1 |
| 15 | Launceston General Hospital | TAS | Stan Gauden | Not active | TBC | - | - |
| Total recruitment | | | | | | 53 | 13 |



COGNO
COOPERATIVE TRIALS GROUP
FOR NEURO-ONCOLOGY

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
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STUDY & TRIAL UPDATES

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

Recruitment for the CATNON study closed on 17 Sep 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 with the cut-off date of 31 May 2015. The database lock occurred on 4 May 2016. The efforts of our Australian sites was noted by the EORTC and as always, very much appreciated.

Professor Martin van den Bent (study coordinator—EORTC) has presented the CATNON trial at the ASCO Conference on the 3 June 2016 and discussed the latest safety data.

Joe Levitt is available to provide any information that you may require and can be reached by emailing any questions or requests to catnon@ctc.usyd.edu.au.

NEW CONCEPTS/TRIALS IN DEVELOPMENT

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.

MEMBERSHIP UPDATE

COGNO now has 479 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 TEAM UPDATE



We welcome Michelle Parry who will gradually be taking over Kate Sawkin's role as COGNO's Associate Oncology Program Manager (Development). After six years as a research scientist for the CSIRO and the University of Sydney, Michelle commenced her clinical trials career at the ANZBCTG. Since joining the NHMRC Clinical Trials Centre in 2005, Michelle has worked in a range of roles including Trial Coordinator, Clinical Data Project Manager and Translational Research Officer. Many of you will already know Michelle from her stint as acting COGNO Associate Oncology Program Manager in 2008, and organiser of the inaugural COGNO strategic planning meeting held that year. Michelle is now looking forward to bringing her protocol development experience and project management skills back to the COGNO team. When not at the Clinical Trials Centre, Michelle enjoys the gym, bushwalking and 4WD touring.

COGNO IDEAS GENERATION WORKSHOP



On the 23 May COGNO held the third annual Ideas Generation Workshop in Sydney. The workshop was convened by Dr Mustafa Khasraw (Medical Oncologist and COGNO Clinical Lead) and Dr Zarnie Lwin (Medical Oncologist), and attended by invited COGNO members. Nine ideas for new trials across a range of disciplines were proposed and discussed amongst the group. The event was a fantastic opportunity for members to receive feedback on their ideas in an informal setting, and to network with other COGNO members. COGNO will continue to work with the attendees on their ideas, and we hope to see some of them submitted for review at

the next SAC meeting at the COGNO ASM. Thank you to everyone involved in organising and attending the event; it was a very productive day and we are already looking forward to the 2017 workshop.



QOL OFFICE CHECKLIST OF INSTRUCTIONS FOR THE ADMINISTRATION OF PATIENT REPORTED OUTCOME MEASURES

The QOL Office is pleased to announce the release of its 'Checklist of instructions for the administration of Patient Reported Outcome (PRO) Measures'. This checklist has been developed over several years, with input from experts, literature reviews and Cancer Clinical Trials Group (CCTGs). The Checklist aims to assist CCTGs in developing instructions for site coordinators working on CCT-led trials for administering PRO questionnaires in a standardised manner. There are two parts to this checklist: 1) paper-based (hardcopy) PRO administration of questionnaires (27 checklist items); 2) electronic PRO administration (25 items). The Checklist (Version 1) is now available on the QOL Office website: <http://www.pocog.org.au/content.aspx?page=qolresources>. The QOL Office would be grateful if CCTGs and CCTG members could begin using the Checklist for newly activated studies and provide feedback or ideas for improvement to qol.office@sydney.edu.au.

REMINDERS/ADDITIONAL INFORMATION

- 24 August 2016 - QoL and Utility Measures in Cancer Research Workshop, Aerial Function Centre, UTS, Sydney, Australia <http://www.isporac.org/events/qolwks/>
- 11-15 September 2016 - ASNO-COGNO Scientific Meeting 2016, Sheraton on the Park, Sydney, Australia <http://asnocogno2016.org.au/>
- 15-17 November 2016 - COSA's 43rd ASM/ANZBCTG's 38th ASM, Gold Coast Convention and Exhibition Centre, Australia <http://cosa2016.org/>
- 17-20 November 2016 - SNO, Fairmont Scottsdale Princess, Scottsdale, USA <http://www.soc-neuro-onc.org/>
- 24 November 2016 - ACTA 2016 National Summit, Melbourne Convention and Exhibition Centre, Australia <http://www.clinicaltrialsalliance.org.au/>



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