

Dear ANZCNS Members,

WELCOME TO THE ANZCNS E-NEWSLETTER FOR SEPTEMBER 2023

ANZCNS 11th ANNUAL SCIENTIFIC MEETING (ASM)

It was great to see so many friendly faces last week at the 11th ANZCNS ASM. A very big thank you to the organisers and congratulations. Looking forward to the 12th ASM at Queenstown, dates to be announced.

ANZCNS TRAINEE PRESENTATION PRIZES

It has come to our notice that one of the prizes awarded at the ASM went to a presenter who is now a consultant and not eligible for the award. We thank that recipient, and other trainees for bringing that to our notice. We apologise for the error and have now amended the prize list as per the judges scores;

1st – Dr Bhanu Bommegowda
2nd – Dr Rachel Wong
3rd – Dr Chien Yen Poh

We congratulate all the prize winners, and all trainees who had their abstracts chosen for platform or poster presentation.

MEMBERSHIP SUBSCRIPTION FOR 2023/2024

Membership renewals for the 2023/2024 membership cycle are now due.

You should receive an email via MemberPress to renew your subscription – following the same process as last year.

For any questions about the membership, please contact the ANZCNS office at admin@anzcns.org.au.

KATE SINCLAIR MEMORIAL RESEARCH SCHOLARSHIP

Congratulations to Dr Emma Macdonald-Laurs for this year's Kate Sinclair Memorial Research Scholarship. We will look forward to learning more on the outcomes of your research.

JOB OPPORTUNITIES

NEW: STAFF SPECIALIST POSITIONS AT SYDNEY CHILDREN'S HOSPITAL, RANDWICK

One is a permanent 0.5FTE position split between Campbelltown Hospital and SCH, Randwick and the other is 12 months 0.6FTE at SCH, Randwick. Please see link below and forward any question you have to Dr Hugo Sampaio at hugo.sampaio@health.nsw.gov.au

<https://jobs.health.nsw.gov.au/schn/jobs/schn-staff-specialist-neurology-randwick-and-campbelltown-ecredential-222775>

<https://jobs.health.nsw.gov.au/schn/jobs/schn-temporary-staff-specialist-neurology-sch-ecredential-222759>

Applications close on Monday 1/10/23.

PRIVATE PRACTICE

I am looking for a Full time Paediatric neurologist to join my private practice (Queensland paediatric specialist) in South East Queensland. Please contact Dr Harry Singh on mobile or via email to discuss options and expression of interest.

Email: drsinghharry@icloud.com

Mobile: 0403411811

Regards

Dr Harry Singh, Paediatric Neurologist, Associate Professor and Clinical Lead Bond University Gold Coast

RACP ANNOUNCEMENTS

FOCUS GROUPS FOR TRAINEES

The RACP is organising focus groups for trainees to "Share trainee experiences of working with people with cognitive disability" and are hoping to recruit Paediatric Neurology trainees. Please see [EOI link](#).



From 2023

The Medical Board of Australia has released its revised [Registration Standard - Continuing Professional Development](#)'.

The Medical Council of New Zealand's [Strengthened Recertification requirements](#) will also commence from 2023.

To align with the new standards, the RACP will implement changes from January 2023 through a revised MyCPD Framework.

As always, please don't hesitate to contact the CPD Team if you have any questions – we're here to help.

AU: 1300 697 227 or MyCPD@racp.edu.au

NZ: 64 4 460 8122 or MyCPD@racp.org.nz

RESEARCH

NEW: ESTABLISHING EXPERT OPINION TO REACH A CONSENSUS ON HOW TO BEST DEFINE AND INVESTIGATE DEVELOPMENTAL REGRESSION IN CHILDREN

The study aims to gather information from parents and caregivers with lived experience and clinicians to achieve a consensus for definitions, assessments and investigations for children presenting with developmental regression.

Your participation will ensure a patient and family-centred approach to clinical practice in this field and/or expert clinical perspectives. The way you answer each question will tailor the questions that follow so they are suited to your experience.

Specifically, we would like your opinion for this and one to two more surveys sent via email using Qualtrics. Each survey should take up to 20 minutes to complete. Thank you for considering participation. Please click on the link below or use the QR code to view our participant information sheet and, if you wish, commence the first survey. Please direct any questions about this research to Prof Michael Fahey. Ethics approval has been granted by Human Research and Ethics Committee (HREC) of Monash Health.

https://monashred.au1.qualtrics.com/jfe/form/SV_9LkhNuBo0GbPtsO



CLINICIAN SURVEY FOR COL4A1/2 GENE VARIANTS

Doctors who diagnose and/or manage individuals with *COL4A1/2* gene variants are invited to take part in a study exploring the variable expressivity and reduced penetrance of these variants. To participate, please notify your patients who have a *COL4A1/2* variant and ask if they are happy for you to share their clinical information with the research team.

If they are happy to participate, and with their permission, please send the research team their contact information (phone number and email address). This will allow the research team to contact them directly for consent. Once consent from your patient is received, you will be sent a link to an online survey which should take 10-15 minutes to complete.

This study is facilitated by Genetic Counsellor Chaya Goldman (chaya.goldman@monashhealth.org), under the supervision of Paediatric Neurologist Professor Michael Fahey. Ethics approval has been granted by Human Research and Ethics Committee (HREC) of Monash Health.

CLINICIAN SURVEY REGARDING KETOGENIC DIET

This short survey of Australian and New Zealand Neurologists (both paediatric and adult) is being undertaken as part of Dr Tania Farrar's PhD project. It is designed to assess current practices with regards to Ketogenic Diet Therapy for patients with epilepsy. We hope that we can use the information gained to improve patient and clinician access to this therapy by better understanding the current knowledge and limitations faced by Neurologists in Australia and New Zealand and the impact this has on their decision to offer this therapy to patients. The survey has undergone ethics review (Ethics Approval Number 2022/PID006898 – 2022/ETH00623).

I appreciate you taking the time to complete the survey and hope it will improve our patients care in the future. Linked to the survey: <https://www.surveymonkey.com/r/KDTWH2022>. For information, please contact Dr Tania Farrar at taniafarrar@hotmail.com

MASSIMO'S MISSION, a MRFF funded leukodystrophy project

Unfortunately, we are no longer able to offer funding for genomic testing for either historical or current patients with undiagnosed white matter disorders.

We still encourage you to contact us if you have a patient with a white matter disorder (with or without a genetic diagnosis) to:

1. Assist with clinical, imaging and genomic interpretation if required.
2. Discuss patient involvement in the national patient registry.
3. Discuss eligibility for emerging treatments and clinical trials.

Please do not hesitate to contact Rick Leventer at richard.leventer@rch.org.au with a cc to program coordinator Eloise Uebergang on (03) 8341 6382/ Eloise.Uebergang@mcri.edu.au if you have any questions. Please also see our new website for the Australian Leukodystrophy Clinical and Research Program – leukonet.org.au.

THE INVESTIGATION AND TREATMENT OF FIRES

Dear colleagues,

A consortium of experts have recently published recommendations for the investigation and treatment of FIRES. We are attaching those recommendations.

A group of ANZCNS members are motivated to try to implement these recommendations where appropriate throughout Australasia, and to create a detailed patient registry, very probably tying in with international efforts with respect to the registry.

To focus interest and involvement we are also considering a trial of a neuroprotective agent along with the registry.

Please would you feed back to our group your thoughts on the recommendations, particularly table 3 acute treatment recommendations.

You might agree with some but not all of those recommendations.

Would you please indicate what resources you have in your center for early and prolonged cEEG and for early ketogenic diet.

Would you please indicate whether you would be interested in registering patients in a patient registry and whether you would be interested in participating in a clinical trial of a neuroprotective agent, csf cytokines, EEG biomarkers?

If you would like to join our group please let us know.

Best regards,

Cia Sharpe, Stephen Malone, Michaela Waak, Kate Riney, Hannah Jones, Russel Dale, Adriane Sinclair and Anita Cairns

AUSTRALIAN CHAPTER OF THE YOUNG EPILEPSY SECTION OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY (THE ILAE-YES)

The ILAE-YES is a world-wide organisation of young people in the early stages of a career focused on the care of people with epilepsy, and/or epilepsy research:

<https://www.ilae.org/about-ilae/structure-and-working-groups/commissions-and-sections/young-epilepsy-section-yes?amp;=amp%3B>

We are trying to recruit more clinicians and researchers to join the Australian chapter of the ILAE-YES with the hope of fostering a national network of individuals interested in epilepsy research, to promote research collaborations, network and share information on relevant grant and scholarship opportunities.

NEWBORN BRAIN SOCIETY (NBS)

I am writing to introduce you to the Newborn Brain Society, (NBS) a non-profit organization with a mission to advance newborn brain care through international multidisciplinary collaboration, education, and innovation among clinicians, scientists, and parents.

The NBS has developed outstanding resources, including:

- o Weekly **webinars** available free to the public and archived online for members
- o Review **publications** covering important topics in Neonatal Neurology including a double issue on the management of neonatal encephalopathy in Seminars of Fetal and Neonatal Medicine
- o **Resources** for research and quality improvement projects

Membership is free for trainees!

I am attaching a resource page with information that can be distributed further.

Please do not hesitate to reach out if you have questions.

Hannah C. Glass, MDCM, MAS (*she/her/hers*)
Professor Neurology, Pediatrics, Epidemiology & Biostatistics
Director, Neonatal Neurocritical Care Services
UCSF Benioff Children's Hospital
<http://profiles.ucsf.edu/hannah.glass>

NATIONAL DELEGATE FROM AUSTRALIA TO JOIN AOCNA

Professor Lakshmi Nagarajan has expressed her wish to stepdown from her role as national delegate between AOCNA and ANZCNS. Members interested ideally would be someone senior/ mid-level, who has had some academic/ administrative, executive roles in Australia. National delegates meetings are held during the congresses (F2F) and also outside of it (often on zoom). She would like a member of the ANZCNS to take this position. Please reach out to discuss if interested in the position, Lakshmi.Nagarajan@health.wa.gov.au.. We thank Lakshmi for holding this position for many years.

UPCOMING CONFERENCES for 2023 and 2024

52nd CHILD NEUROLOGY SOCIETY ANNUAL MEETING

VENUE: Vancouver, Canada

DATE: 4-7th October 2023

ESA 37th ANNUAL SCIENTIFIC MEETING

THEME: Epilepsy in Indigenous Peoples' and 'Epilepsy Across the Lifespan'.

VENUE: Auckland, New Zealand

DATE: 1st-3rd November 2023

AMERICAN EPILEPSY SOCIETY ANNUAL MEETING

VENUE: Orlando, USA

DATE: 1st-5th December 2023

AMERICAN SOCIETY OF PEDIATRIC NEURORADIOLOGY

VENUE: San Diego, USA

DATE: 12th-14th January 2024

EPILEPSY SOCIETY AUSTRALIA CLINICAL EPILEPSY COURSE AND ANZAN EEG COURSE

VENUE: Mercure North Melbourne and Royal Children's Hospital

DATE: 9th-11th February 2024

INTERNATIONAL PAEDIATRIC STROKE ORGANISATION CONFERENCE

VENUE: SICKKIDS, Toronto, Canada

DATE: 22th-24th March 2024

18th INTERNATIONAL CHILD NEUROLOGY CONGRESS INTERNATIONAL CHILD NEUROLOGY ASSOCIATION

VENUE: Cape Town, South Africa

Date: 6th-10th May 2024

Please consider joining membership. Lifetime membership is free. Membership application can be accessed at the following link:

[Join the ICNA \(icnapedia.org\)](https://icnapedia.org)

AUSTRALIAN AND NEW ZEALAND ASSOCIATION OF NEUROLOGISTS (ANZAN) ANNUAL SCIENTIFIC MEETING

Venue: Adelaide Convention Centre

Date: 22nd-24th May 2024

12TH ANZCNS ANNUAL SCIENTIFIC MEETING

Venue: Queenstown

Date: September, 2024

ESA 37th ANNUAL SCIENTIFIC MEETING

VENUE: Grand Chancellor Hobart Hotel

DATE: 6th-8th November 2024

53rd CHILD NEUROLOGY SOCIETY ANNUAL MEETING

VENUE: San Diego, California, USA

DATE: 11th-14th November 2024

EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY CONGRESS

VENUE: Munich, Germany

DATE: 8th-12 July 2025

THE ASIAN AND OCEANIAN CHILD NEUROLOGY ASSOCIATION MEETING

VENUE: TBA

DATE: 5-7th September 2025

AOCNA GRAND ROUND

There are Paediatric Grand rounds hosted (in turn) by the countries in our region. PCH Perth, WA, on behalf of Australia has presented the last two years. It would be good for other centres to be involved and present. The cases are interesting and the discussions good. The National delegate(ND) from Australia can solicit presentations from the different children's hospitals. The AOCNA communicates the timing of the webinar/topic to the ND, who is then expected to disseminate the information to the child neurologists in their country. The dates of the grand rounds are predetermined, the countries have volunteered for different months and that is also known well in advance, the time and topic is broadcasted closer to the date of the webinar. Dr Jithangi Wanigasinghe (jithangi@gmail.com) is the new coordinator of the Grand Rounds.

If anyone is interested in presenting at the AOCNA grand round in 2024, please get in touch with Lakshmi.Nagarajan@health.wa.gov.au.

Please also consider joining membership to AOCNA. Very few Australian Child Neurologists are members of AOCNA. We are part of this region and it is important for us to be engaged with AOCNA. The cost of lifetime membership is a one-off fee of US\$100. All ANZCNS members are encouraged to apply. Membership application can be accessed at the following link:

<https://www.gevme.com/aocnamembership>.

EDUCATION AND TRAINING OPPORTUNITIES

PAEDIATRIC BRAIN SCHOOL - AUSTRALIA AND NEW ZEALAND

Generally held on a third Tuesday each month.

- Tuesday, October 17th – MOVEMENT DISORDERS 2
- Tuesday, November 21st - ATAXIA

For those not on mailing list already, please contact the college (Neurology@racp.edu.au) to be added to the list.

BRITISH PAEDIATRIC NEUROLOGY ASSOCIATION PAEDIATRIC EPILEPSY TRAINING (BPNA PET) COURSES IN 2023-TENTATIVE DATES

Please advertise the dates to your departments for paediatricians, trainees (PET1 and PET2), selected GPs, Emergency physicians, and Neurology/Epilepsy nurses (PET1):

- PET1; Monday 6th November (The Bright Alliance Building, Randwick, Sydney)
- PET2; Tuesday 7th – Wednesday 8th November (The Bright Alliance Building, Randwick, Sydney)

To register, please see below link.

[BPNA and ANZCNS PET Course November 2023 \(ivvy.com.au\)](https://www.ivvy.com.au)

For those interested in joining the faculty, please contact Simone Ardern-Holmes simone.ardernholmes@health.nsw.gov.au.

ANZCNS CLINICAL CASE FORUM 2023 and new 2024 dates

Tuesday, October 24th	Queensland Children's Hospital, Brisbane (2)
Tuesday, November 28th	Monash Medical Centre
Tuesday, February 20th	The Children's Hospital at Westmead
Tuesday, March 19th	Queensland Children's Hospital, Brisbane
Tuesday, April 16th	Sydney Children's Hospital
Tuesday, May 21st	Starship Children's Hospital, Auckland
Tuesday, June 25th	Perth Children's Hospital
Tuesday, July 23rd	Royal Children's Hospital Melbourne
Tuesday, August 20th	John Hunter Children's Hospital, Newcastle
Tuesday, September 24th	The Children's Hospital at Westmead (2)
Tuesday, October 22nd	Queensland Children's Hospital, Brisbane (2)
Tuesday, November 26th	Monash Medical Centre

Training sites and site co-ordinator contact name:

Gold Coast University Hospital: **Harry Singh**

John Hunter Children's Hospital, Newcastle: **Christina Miteff**

Monash Medical Centre, Melbourne: **Michael Fahey/Shabeed Chelakkadan**

Perth Children's Hospital: **Mohd (Najm) Khan and Bhanu Bommegowda**

Queensland Children's Hospital, Brisbane: **Anita Cairns/Sophie Calvert/Rebecca Leung**

Royal Children's Hospital, Melbourne: **Elizabeth Cole**

Royal Hobart Hospital: **Tyson Ware**

Starship Children's Hospital, Auckland: **Cynthia Sharpe/Gina O'Grady**

Sydney Children's Hospital, Sydney: **Janette Lee**

Wellington Hospital /University of Otago: **Erik Andersen/Lynette Sadleir**

Westmead Children's Hospital, Sydney: **Joanne Davidson**

I will endeavour to send out a newsletter every 2 months; the next will be in November. If there are any urgent announcements, I'll be more than happy to accommodate and alter the schedule. So if any members have brief paragraphs of news, stories or items of interest please forward them to Lejla (admin@anzcns.org.au) or Hooi Ling Teoh (hooiling.teoh@health.nsw.gov.au).

Thank you very much for reading and hope everyone is keeping well.

Kind regards,
Hooi Ling and Lejla