

Dear ANZCNS Members,

## WELCOME TO THE ANZCNS E-NEWSLETTER FOR JULY 2023

### ANZCNS 11th ANNUAL SCIENTIFIC MEETING (ASM)

The [registration](#) for the 11<sup>th</sup> ASM, held between 13<sup>th</sup>-15<sup>th</sup> September at the Adelaide Convention Centre, is still open.

Early Bird registration closes this **Monday, 31<sup>st</sup> July**.

***Please note that the single day registration has been discounted for all trainees.***

You are also welcome to [register](#) for the Trainee Day following the ASM on Friday afternoon 15<sup>th</sup> and all-day Saturday, 16<sup>th</sup> September 2023.

The overall theme will be **"Growing older and old before their time"**. The five planned symposia will focus on neurocritical care, dementia, neuro-oncology, adolescent neurology and headaches/intellectual disability. There again will be a trainee's day and the programme are sure to be another success.

Regular updates and latest program can also be accessed via [ASM website](#).

We hope you can join us in Adelaide!

***Please note the Annual General Meeting (AGM) for ANZCNS will be held on Wednesday, 13<sup>th</sup> September at 5.00pm AECT (in person and virtually).***

### MEMBERSHIP SUBSCRIPTION FOR 2023/2024

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

You should have received an email via MemberPress to renew your subscription – following the same process as last year. Any outstanding fees will be automatically added to the fee for the next membership cycle.

You can also pay your membership fees with this year's meeting registration.

For any questions about the membership, please contact the ANZCNS office at [admin@anzcns.org.au](mailto:admin@anzcns.org.au).

### FELLOW JOB OPPORTUNITIES-McGill University Health Centre-Montreal Children's Hospital

As a result of last year's campaign, we are excited to welcome seven non-Ministry-of-Health funded "Shevell Scholars" in 2023. We are pleased to announce that applications are now open for the 2024 academic year. Successful applicants can once again benefit from fully funded opportunities. They need not come with their own sources of funding.

The deadline for applications is September 1, 2023. Information about training programs, admissions, requirements, and how to apply may be found in the links (see attached), or by contacting Natalie Ross ([natalie.ross@muhc.mcgill.ca](mailto:natalie.ross@muhc.mcgill.ca)).

## JOB OPPORTUNITIES

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](mailto: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.** Further communications on the changes will be released throughout the second half of 2021 and in 2022.

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](mailto:MyCPD@racp.edu.au)

NZ: 64 4 460 8122 or [MyCPD@racp.org.nz](mailto:MyCPD@racp.org.nz)

## RESEARCH

### CLINICIAN SURVERY 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](mailto: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](mailto: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](mailto:richard.leventer@rch.org.au) with a cc to program coordinator Eloise Uebergang on (03) 8341 6382/ [Eloise.Uebergang@mcri.edu.au](mailto: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](http://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>

## UPCOMING CONFERENCES

### **THE ASIAN AND OCEANIAN CHILD NEUROLOGY ASSOCIATION MEETING**

VENUE: Bangkok, Thailand

DATE: 4-6<sup>th</sup> August 2023

### **AUSTRALIAN BRAIN CLUB**

Bringing Fetal, Neonatal & Paediatric Brain Researchers & clinicians together

VENUE: Melbourne Marriott Hotel Docklands

DATE: 17-18<sup>th</sup> August 2023

(flyer attached)

### **ANZCNS 11th ANNUAL SCIENTIFIC MEETING**

VENUE: Adelaide Convention Centre

DATE: 13-15<sup>th</sup> September 2023

### **52<sup>nd</sup> CHILD NEUROLOGY SOCIETY ANNUAL MEETING**

VENUE: Vancouver, Canada

DATE: 4-7<sup>th</sup> October 2023

### **ESA 37<sup>th</sup> ANNUAL SCIENTIFIC MEETING**

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

VENUE: Auckland, New Zealand

DATE: 1<sup>st</sup>-3<sup>rd</sup> November 2023

### **AMERICAN EPILEPSY SOCIETY ANNUAL MEETING**

VENUE: Orlando, USA

DATE: 1<sup>st</sup>-5<sup>th</sup> December 2023

### **18<sup>th</sup> INTERNATIONAL CHILD NEUROLOGY CONGRESS INTERNATIONAL CHILD NEUROLOGY ASSOCIATION**

VENUE: Cape Town, South Africa

Date: 6-10<sup>th</sup> May 2024

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

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

### **53<sup>rd</sup> CHILD NEUROLOGY SOCIETY ANNUAL MEETING**

VENUE: San Diego, California, USA

DATE: 11-14<sup>th</sup> November 2024

## **AOCNA GRAND ROUND**

**If anyone is interested in presenting at the AOCNA grand round in 2024, please get in touch with [Lakshmi.Nagarajan@health.wa.gov.au](mailto:Lakshmi.Nagarajan@health.wa.gov.au).**

Please also consider joining membership to 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:

[Aocna | The Asian and Oceanian Child Neurology Association](#)

## **EDUCATION AND TRAINING OPPORTUNITIES**

### **PAEDIATRIC BRAIN SCHOOL - AUSTRALIA AND NEW ZEALAND**

- Tuesday, August 1st – Dr Richard Leventer, Cortical malformations followed by Cerebellar malformations
- Tuesday, August 15th – CNS MALFORMATIONS 2
- Tuesday, September 19th – MOVEMENT DISORDERS 1
- 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](mailto: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 6<sup>th</sup> November, UNSW
- PET2; Tuesday 7<sup>th</sup> – Wednesday 8<sup>th</sup> November, UNSW

For those interested in joining the faculty, please contact Simone Ardern-Holmes ([simone.ardernholmes@health.nsw.gov.au](mailto:simone.ardernholmes@health.nsw.gov.au)).

### **ANZCNS CLINICAL CASE FORUM 2023**

Tuesday, 22<sup>nd</sup> August – John Hunter Children's Hospital

Tuesday, 26<sup>th</sup> September – The Children's Hospital Westmead

Tuesday, 24<sup>th</sup> October – Queensland Children's Hospital

Tuesday, 28<sup>th</sup> November – Monash Medical Centre

#### *Site Training Co-ordinators:*

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

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

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

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

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

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

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

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

Gold Coast University Hospital: **Harry Singh**  
Royal Hobart Hospital: **Tyson Ware**  
Monash Medical Centre, Melbourne: **Michael Fahey/Shabeed Chelakkadan**

I will endeavour to send out a newsletter every 2 months; the next will be in September. 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](mailto:admin@anzcns.org.au)) or Hooi Ling Teoh ([hooiling.teoh@health.nsw.gov.au](mailto:hooiling.teoh@health.nsw.gov.au)).

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

Kind regards,  
Hooi Ling and Lejla

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