

Dear ANZCNS Members,

WELCOME TO THE ANZCNS E-NEWSLETTER FOR NOVEMBER 2022

A huge congratulations to Dr Rachel Wong for her appointment as the new ANZCNS trainee board member and ETC rep. Thank you to Dr Ellen Hurley for your contributions to the role.

ANZCNS 11TH ANNUAL SCIENTIFIC MEETING (ASM)

We are pleased to advise the ANZCNS 11th ASM will be held between 13th-15th September 2023, at the Adelaide Convention Centre.

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.

We hope you can join us in Adelaide!

MEMBERSHIP SUBSCRIPTION UPDATE

You should have received an email reminder (from MemberPress) for payment of membership fees for the new 2022/2023 cycle.

Please let us know if you would like us to re-send the email.

Members are also reminded to ensure their ANZCNS membership dues are up to date including previous years.

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

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

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](#).



2021 and 2022

There are no changes to CPD requirements in 2021 and 2022. Please see the RACP [2021 MyCPD Framework](#) for further details.

The [additional requirements for Aotearoa New Zealand Fellows](#) also remain in place.

The College's CPD resources are available in the [MyCPD Interactive Handbook](#) and the [Online Learning Resources platform](#).

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

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

RESEARCH

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

TRENDS IN DIAGNOSIS AND MANAGEMENT OF ESES (ELECTRICAL STATUS EPILEPTICUS OF SLEEP).

We wish to explore current opinion and practice like to seek your feedback the Australian and New Zealand child neurology fraternity regarding ESES/CSWS and EESES/ECSWS. ESES (*electrical status epilepticus of sleep*) also called CSWS (*continuous spike wave during slow wave sleep*) is a term coined to characterise marked activation of epileptiform discharges on EEG during slow wave sleep. ESES/CSWS may be associated with epileptic encephalopathy and then referred to as epileptic encephalopathy with EESES/ECSWS. The EEG and clinical criteria used to define/diagnose ESES/CSWS and EESES/ECSWS vary widely.

We wish to explore current opinion and practise among the Australian and New Zealand child neurology fraternity regarding ESES/CSWS and EESES/ECSWS. We thank you for participation and contribution in this survey.

- Please click on the link below or scan the QR code to access the survey.
- It should take between 5-10 minutes to complete.

Survey Link: <https://datalibrary-rc.health.wa.gov.au/surveys/?s=LRN3H9AYF99DLYWC>

QR Code:



For information, please contact Dr. Snehal Shah | Paediatric Neurology consultant | Department of Neurology. Email: snehal.shah@health.wa.gov.au

PATIENT AND HEALTH PROFESSIONAL PERSPECTIVES ON GENETIC SCREENING FOR ADRENOLEUKODYSTROPHY

Dr Chris Jacobs at chris.jacobs@uts.edu.au from UTS is conducting a research to canvas the perspectives of people affected by Adrenoleukodystrophy (ALD) – patients and/or those at risk of ALD as well as those involved in their care (health professionals and their carers) – on the nature and level of care provided currently, including attitudes to screening/early detection, for ALD. Participation in this study will involve a one off semi-structured interview online or by telephone. The interview will last for 30-60 minutes, depending on how much you would like to say about your views and experiences. Please contact him if interested to participate.

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/topical-commissions/yes/young-epilepsy-section-yes>

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

AMERICAN SOCIETY OF PEDIATRIC NEURORADIOLOGY

VENUE: New Orleans, USA

DATE: 13-15th January 2023

ESA CLINICAL EPILEPSY COURSE AND ANZAN EEG COURSE

VENUE: Westmead Innovation centre, Uni Sydney Conference Centre

DATE: 10-11th February 2023

AMERICAN ACADEMY OF NEUROLOGY ANNUAL MEETING

VENUE: Boston and Virtual, USA

DATE: 22-27th April 2023

INTERNATIONAL PAEDIATRIC STROKE ORGANISATION CONFERENCE

VENUE: Virtual

DATE: 28-29th April 2023

EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY CONGRESS

VENUE: Prague, Czech Republic

DATE: 20-24th June 2023

THE ASIAN AND OCEANIAN CHILD NEUROLOGY ASSOCIATION MEETING

VENUE: Bangkok, Thailand

DATE: 4-6th August 2023

ANZCNS 11TH ANNUAL SCIENTIFIC MEETING

Venue: Adelaide Convention Centre

Date: 13-15th September 2023

52nd CHILD NEUROLOGY SOCIETY ANNUAL MEETING

VENUE: Vancouver, Canada

DATE: 4-7th October 2023

ESA 37th ANNUAL SCIENTIFIC MEETING (preliminary)

VENUE: Auckland, New Zealand

DATE: 1-3rd November 2023

AMERICAN EPILEPSY SOCIETY ANNUAL MEETING

VENUE: Orlando, USA

DATE: 1-5th December 2023

18th INTERNATIONAL CHILD NEUROLOGY CONGRESS

INTERNATIONAL CHILD NEUROLOGY ASSOCIATION

VENUE: Cape Town, South Africa

Date: 6-10th 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://www.icnapedia.org)

53RD CHILD NEUROLOGY SOCIETY ANNUAL MEETING

VENUE: San Diego, California, USA

DATE: 11-14th November 2024

AOCNA GRAND ROUND

30th Nov 22: Interesting cases from a busy Pediatric Epilepsy Monitoring Unit

Time: 9.30 AM - 11:00 AM (Tehran Time / GMT+03:30)

Speakers: Prof. Mahmoud Mohammadi, Dr. R.Shervin Badv, Dr. M. Javadzadeh and Z.Rezaei

Join Zoom Meeting

<https://us02web.zoom.us/j/5626692683?pwd=NGNSL042ZzYxbmI1bFkwQ3BIUVpTUT09>

Meeting ID: 562 669 2683

Passcode: AOCNAGdRd

28th Dec 22: Segawa Disease

Time: 6pm-7pm (Japan Time/UTC+9)

Speaker: Dr. Kyoko Hoshino, Director, Segawa Memorial Neurological Clinic for Children

Join by ZOOM

>>Meeting ID : 912 9472 5082

>>Meeting Passcode: 685103

Please consider joining membership. 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

Dates for 2023 will be available soon. Aiming to keep the same schedule which is a 3rd Tuesday of the month, with a few exceptions due to public holidays etc.

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 and PET 2; Monday 1st – Wednesday 3rd May (Likely Westmead Campus, Sydney)
- PET1; Monday 28th August (Westmead or Randwick, Sydney TBA)
- PET2; Tuesday 29th – Wednesday 30th August (TBA)

Please also note PET3 is expected to be offered in NZ on 17-18th October for existing faculty to observe remotely, before teaching the course.

For those interested in joining the faculty, please contact Simone Ardern-Holmes (simone.ardernholmes@health.nsw.gov.au), and diarise course dates to observe before attending Instructor Training Day on 3 or 6 November 2023 (date to be confirmed).

ANZCNS CLINICAL CASE FORUM 2022

20th December – Cancelled

ANZCNS CLINICAL CASE FORUM 2023

21st February - The Children's Hospital at Westmead

21st March - Queensland Children's Hospital

18th April - Sydney Children's Hospital

23rd May - Starship Children's Hospital, Auckland

27th June - Perth Children's Hospital

25th July - Royal Children's Hospital Melbourne

22nd August - John Hunter Children's Hospital, Newcastle

26th September - The Children's Hospital at Westmead

24th October - Queensland Children's Hospital

28th November - Monash Medical Centre

Site Training Co-ordinators:

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

Royal Children's Hospital, Melbourne: **Nicola Fearn**

Sydney Children's Hospital, Sydney: **Emily Innes**
Westmead Children's Hospital, Sydney: **Joanne Davidson**
Queensland Children's Hospital, Brisbane: **Anita Cairns/Sophie Calvert/Tariq Gubara**
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 January. 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