

Dear ANZCNS Members,

WELCOME TO THE ANZCNS E-NEWSLETTER FOR FEBRUARY 2021.

Firstly, a very happy new year to everyone. I hope everyone have started the new year well rested and ready for the challenges for 2021. Just a few new announcements for this newsletter. Thank you to those who have contributed.

I will endeavour to send out a newsletter every 2months, the next will be in April. 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) and we are happy to include them in our newsletters.

SUBSCRIPTION REMINDER

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

To pay for membership for previous years, or to check if your membership is current, please contact the ANZCNS office at admin@anzcns.org.au.

To pay subs for the last membership cycle (2019/2020) please [click here](#).

To renew for 2020/2021 and/or update your details please [click here](#).

ANZCNS 9TH ANNUAL SCIENTIFIC MEETING-NEW DATES

The 9th Annual Scientific Meeting of the ANZCNS will be held between Monday, 13th – Wednesday, 15th September 2021, at the Pullman Albert Park, Melbourne.

NEW ANNOUNCEMENTS

ALEX SCOLLARD MEMORIAL PhD SCHOLARSHIP together with SAVE OUR SONS

Application now open and will close 12th February 2021. Please see attached separate PDF for more information.

MASSIMO'S MISSION, a MRFF funded leukodystrophy project.

If you have a historical patient who remains undiagnosed after local genomic testing (e.g. panel or singleton WES), there are funds to upgrade to trio WES or trio WGS.

If you are seeing a new patients in clinic, we can offer trio WES or trio WGS up front after initial basic screening investigations. Depending on the clinical urgency, the genomic testing could be done as a RAPID test (15 working day turnaround). If there is no clinical urgency, then the standard time for a trio WES or trio WGS is approximately 3 months.

Please do not hesitate to contact Rick Leventer at richard.leventer@rch.org.au or Eloise Uebergang on (03) 8341 6382/ Eloise.Uebergang@mcri.edu.au if you have any questions or to check if they are eligible for genomic testing through Massimo's Mission.

CLINICAL PRACTICE OF CHILD NEUROLOGY

Mac Keith Press and the European Paediatric Neurology Society (EPNS) present two EACCME® accredited online learning courses that provide authoritative advice on managing neurological disorders presenting in infancy. For more information, please visit <https://courses.mackeith.co.uk>

If you are a member of ICNA, there is a 20% discount on the courses using coupon code ICNAMEM20.

AZALEA FESTIVAL SYMPOSIUM IN PEDIATRIC NEUROLOGY

This year our topic will focus on "etiological investigation in children with epilepsy". We have many famous speakers from Taiwan and the world, including Ingrid Scheffer, Sinichi Hirose, Russel Dale, and Jo Wilmshurst.

VENUE: Online (Registration is free)

Date: Mar 27-28, 2021.

For more information: <https://forms.gle/vGoeZFLsHuVvwh6LA>

RECURRING ANOUNCEMENTS

RACP ANNOUNCEMENTS

If there are any supervisors and trainees concerned about training this year, please note the change to college requirements for this year. For further questions, please contact the RACP representative:

Australia: Dr Alexandra Johnson at Alexandra.Johnson@health.nsw.gov.au

New Zealand: Dr Gina O'Grady at GinaO@adhb.govt.nz

<https://www.racp.edu.au/news-and-events/covid-19/education-and-training/changes-to-requirements>

RACP NEUROLOGY TEACHING

The RACP has for some time been looking at banking recorded teaching sessions for the trainees. If anyone is interested in recording a teaching session on a neurology topic of their choice, please contact Dr Sampaio: hugo.sampaio@health.nsw.gov.au

RESEARCH

NATURAL HISTORY STUDY OF PATIENTS WITH CANAVAN DISEASE – INVITATION FOR FAMILIES

Aspa Therapeutics, a biotechnology company working to develop a gene therapy for Canavan disease, is enrolling patients in a natural history study called CANinform. The study aims to describe the natural course of Canavan disease and help doctors understand what clinical improvements might look like in patients who receive a potential treatment someday. The study is open to all patients with a diagnosis of Canavan disease. All study assessments will be performed reliably and safely in a remote fashion in the patient's home via video conference. Further information about the study, including how to enrol, is available on the study website www.treatcanavan.com or at www.clinicaltrials.gov [NCT04126005].

Please do not hesitate to contact Rick Leventer at richard.leventer@rch.org.au or the study coordinator Eloise Uebergang on (03) 8341 6382/ Eloise.Uebergang@mcri.edu.au if you have any questions.

For specific questions related to Aspa's clinical program, please email clinicaltrials@aspatx.com.

NATURAL HISTORY STUDY OF PELIZAEUS-MERZBACHER DISEASE (PMD) AT RCH/MCRI – INVITATION FOR FAMILIES

The Murdoch Children's Research Institute, in collaboration with the Children's Hospital of Philadelphia, is studying the natural history of PMD in order to understand how PMD progresses over time in individuals of all ages. This study will involve the collection of information from existing medical records of individuals with PMD with consent from the individual, parent or guardian. The study is retrospective and will not require these individuals to do anything other than provide consent to access medical records.

If you know of a family with a child who has been diagnosed with PMD and they are interested in participating, please pass on their details so that we can contact the family and/or send the information and consent form.

Please do not hesitate to contact Rick Leventer at richard.leventer@rch.org.au or the study coordinator Eloise Uebergang on (03) 8341 6382/ Eloise.Uebergang@mcri.edu.au if you have any questions.

SPINAL MUSCULAR ATROPHY PROJECT-STILL LOOKING FOR PARTICIPANTS

New research project by Associate Professor Michelle Farrar is recruiting participants for a research study called "*Understanding patients and carers decision making in Spinal Muscular Atrophy care.*" The research is being carried out to learn more about what factors (such as benefits of treatment and cost) are important when making decisions related to treatment for Spinal Muscular Atrophy (SMA). It involves a survey that takes about 15-20minutes to complete. The attached link is for the survey: <https://chere.surveyengine.com/survey/441/523>

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.

UPCOMING CONFERENCES

ANZAN EEG COURSE

VENUE: Virtual

DATE: 13th and 14th February 2021

INTERNATIONAL PAEDIATRIC STROKE ORGANISATION

VENUE: Vienna, Austria

DATE: 18th-20th July 2021

16th AOCCN

Venue: Shangri-La, Bangkok. Thailand

Date: 5th-7th August 2021

EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY-POSTPONED to 2022

14th EPNS Congress

Venue: Glasgow, UK

Date: 28 April – 2 May 2022

INTERNATIONAL CHILD NEUROLOGY ASSOCIATION

All members are encouraged to obtain full membership of ICNA. Membership is free and you can find out more from the following link <https://icnapedia.org/register/benefits>

ASIAN AND OCEANIA CHILD NEUROLOGY ASSOCIATION

The ANZCNS met in April 2018 to map a strategic plan for the organization for the next 5 years. This will be circulated to members. One of the resolutions agreed to at that meeting was to bid to host an AOCNA meeting in the coming years. Currently only a very small fraction of the ANZCNS membership base holds AOCNA 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:

<http://www.aocna.org/index.php/en/membership-application>

EDUCATION AND TRAINING OPPORTUNITIES

BPNA COURSE

The ANZCNS and BPNA have taken the decision to postpone the British Paediatric Neurology Association Paediatric Epilepsy Training courses from July this year to early 2021, dates to be advised.

For more details, please contact Simone at simone.ardernholmes@health.nsw.gov.au

INTERNATIONAL PEDIATRIC NEURORADIOLOGY TEACHING NETWORK

The ASPNR offers FREE weekly lecture series in the field of paediatric neuroradiology. Pre-registration is required. The lecture times are not friendly to AEST as it is at 0200 on Sunday but occasionally the lecture times are more suitable.

Link: <https://asprn.org/awards/international-pediatric-neuroradiology-teaching-network/>

ANZCNS CLINICAL CASE FORUM 2021

23rd February - The Children's Hospital at Westmead

23rd March - Queensland Children's Hospital

27th April - Starship Children's Hospital, Auckland

25th May - Sydney Children's Hospital

22nd June - Perth Children's Hospital

27th July - Royal Children's Hospital Melbourne

24th August - John Hunter Children's Hospital, Newcastle

28th September - The Children's Hospital at Westmead

26th October - Queensland Children's Hospital

23rd November - Monash Medical Centre
21st December - Sydney Children's Hospital

Site Training Co-ordinators:

Perth Children's Hospital: **Maina Kava**

Royal Children's Hospital, Melbourne: **Kathryn Irving**

Sydney Children's Hospital, Sydney: **Romain Briest**

Westmead Children's Hospital, Sydney: **Emily Innes**

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

John Hunter Children's Hospital, Newcastle: **Gopi Subramanian**

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**

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

Kind regards,
Hooi Ling and Lejla

Executive Assistant

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