

Dear ANZCNS Members,

WELCOME TO THE ANZCNS E-NEWSLETTER FOR APRIL 2021.

NEW UPDATE!!!

ANZCNS 9TH ANNUAL SCIENTIFIC MEETING

The 9th Annual Scientific Meeting of the ANZCNS will be held **VIRTUALLY** as three half days (1000-1300 AEST) between Monday, 13TH –Wednesday, 15TH September 2021.

Abstract submission is now open, please visit [meeting website](#) for more idetails.

More information to follow.

We are hoping that in 2022, the ANZCNS 10th Annual Scientific Meeting will be on site with Melbourne as host.

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](#).

NEW ANNOUNCEMENTS

PBAC REQUEST FOR ANZCNS ADVICE ON TETRACOSACTIDE

In 2016, The ANZCNS had provided advice stating that while tetracosactide was only rarely used, it was important it remained easily accessible for the treatment of Infantile spasms and Opsoclonus-Myoclonus Syndrome refractory to other therapies. Tetracosactide is currently available on the PBS as a restricted benefit for infantile spasms and hypsarrhythmia.

The ICISS study (Lancet Neurology 2017) did not show superiority of one form of hormonal therapy over another because of lack of randomisation into the oral prednisolone or IM ACTH groups.

The PBAC has requested advice on

- How clinicians have managed during the period of shortage of tetracosactide availability since 1 February 2019
- That the advice provided in 2016 is still current and relevant

We are keen to hear your thoughts on the matter, which will be collated, to a response to the PBAC. Please email manoj.menezes@health.nsw.gov.au by **COV, Friday 23rd April**.

NEW RESEARCH-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.

RACP WOULD LIKE TO REMIND EVERYONE THAT CPD WILL BE REQUIRED FOR 2021

Please review the RACP [2021 MyCPD framework](#) to ensure you are familiar with your requirements and explore the College's CPD resources in the [MyCPD Interactive Handbook](#) and the [Online Learning Resources platform](#).

Please also see [guides and template examples](#) to help understand requirements of Cat 2&3 CPD activities.

As always, please don't hesitate to contact the CPD Team if you have any questions –
AU: 1300 697 227 or MyCPD@racp.edu.au
NZ: 64 4 460 8122 or MyCPD@racp.org.nz

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

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.

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

NEW - 14TH INTERNATIONAL CONGRESS OF INBORN ERRORS OF METABOLISM 2021

VENUE: Hilton Hotel, Sydney and ONLINE

DATE: 21st-23rd November 2021

UPDATED - INTERNATIONAL PAEDIATRIC STROKE ORGANISATION

VENUE: ONLINE

DATE: 19th-21st July 2021

16th AOCCN

Venue: Shangri-La, Bangkok, Thailand

Date: 5th-7th August 2021

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:

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

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>

EDUCATION AND TRAINING OPPORTUNITIES

NEW-UNSW SYDNEY PRACTICAL MEDICAL GENOMICS SHORT COURSE

The [UNSW Sydney Practical Medical Genomics Short Course](#) has been developed for clinicians and clinicians-in-training who are interested in learning about clinical genomics and precision medicine. Attendees will gain knowledge and skills to integrate genomics into their daily practice. The University is taking expressions of interest in the course, so clinicians can register on the [course site](#) now, with the first course set to run online over six weeks during August-September 2021. The live sessions will take place over two weekends, with the rest of the learning being able to be completed when convenient for individual attendees. If interested, please click on the link.

[Practical Medical Genomics | Medicine Short Courses - UNSW Sydney](https://shortcourses.med.unsw.edu.au/course/practical-medical-genomics)(<https://shortcourses.med.unsw.edu.au/course/practical-medical-genomics>).

BPNA COURSE

The ANZCNS and BPNA have taken the decision to postpone the British Paediatric Neurology Association Paediatric Epilepsy Training courses, 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://aspnr.org/awards/international-pediatric-neuroradiology-teaching-network/>

ANZCNS CLINICAL CASE FORUM 2021

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: **Mohd (Najm) Khan**
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**

I will endeavour to send out a newsletter every 2months; the next will be in June. 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.

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

Kind regards,
Hooi Ling and Lejla

Executive Assistant

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