

Dear ANZCNS Members,

## **WELCOME TO THE ANZCNS E-NEWSLETTER FOR AUGUST 2021.**

### **ANZCNS 9TH ANNUAL SCIENTIFIC MEETING**

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

For more information, the latest program and to register please visit the [meeting website](#).

#### **Calling for cases for the meeting;**

On day two of the ANZCNS annual meeting we are looking for presentations for the “diagnostic dilemmas” section. We are seeking two types of cases. For the formal part of the meeting (1215 to 1300) we are seeking 3-4 complex SOLVED cases that had a long or unusual diagnostic journey. Following this (from 1300), we are inviting members to present any undiagnosed cases that they wish to present to their colleagues for input. This will be an optional session outside of the formal program. Please send ideas for your SOLVED cases to Rick Leventer ([richard.leventer@rch.org.au](mailto:richard.leventer@rch.org.au)) and Kat Howell ([katherine.howell@rch.org.au](mailto:katherine.howell@rch.org.au)), and let us know whether you wish to present any UNSOLVED cases for discussion in optional session.

### **ANZCNS ANNUAL GENERAL MEETING**

The AGM will be held virtually on Monday, 13th September 2021 at 0900 AEST via Zoom. An individual calendar invite and AGM documents will be sent out shortly.

### **MEMBERSHIP SUBSCRIPTION UPDATE**

You should have already received an email with information about the new membership portal, and an invitation to set-up a password for your account to renew membership for 2021-2022 cycle. This will be the only account required for your membership moving forward, so it's important you have your password set-up, even if you have paid for your membership with this year's meeting registration.

Please let us know if you did not receive this email or need us to re-send it.

Members are also reminded to ensure their ANZCNS membership dues are up to date including previous years, to remain financial. 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](mailto:admin@anzcns.org.au).

### **RACP ANNOUNCEMENTS**

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

Date: Tuesday, 1300-1500 AEST via Zoom

The launch of paediatric brain school saw Dr Sophie Calvert presenting an awesome lecture on Non-migrainous headache in children. This will be available on the college website for those who missed it.

Upcoming topics:

17th August

Hypomyelinating leukodystrophies - Dr Chloe Stutterd

Demyelinating and dysmyelinating leukodystrophies - Dr Rick Leventer

31st August

New therapeutic options in migraine - Dr Sophie Calvert  
Multidisciplinary headache management - Dr Snehal Shah

Further proposed dates for 2021 (Tuesdays 1-3pm AEST)

21st September  
28th September  
19th October  
26th October  
2nd November  
9th November  
23rd November  
7th December  
14th December

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.

We are on the look-out for speakers for 2022 so please volunteer!!  
Alex Johnson, Victoria, Simone Arden-Holmes and Mark Mackay

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

## **RESEARCH**

### **PATIENT AND HEALTH PROFESSIONAL PERSPECTIVES ON GENETIC SCREENING FOR ADRENOLEUKODYSTROPHY**

Dr Chris Jacobs at [chris.jacobs@uts.edu.au](mailto: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.**

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](mailto:richard.leventer@rch.org.au) or Eloise Uebergang on (03) 8341 6382/ [Eloise.Uebergang@mcri.edu.au](mailto: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](http://www.treatcanavan.com) or at [www.clinicaltrials.gov](http://www.clinicaltrials.gov) [NCT04126005].

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

For specific questions related to Aspa's clinical program, please email [clinicaltrials@aspatx.com](mailto: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](mailto:richard.leventer@rch.org.au) or the study coordinator Eloise Uebergang on (03) 8341 6382/ [Eloise.Uebergang@mcri.edu.au](mailto: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**

#### **50TH CHILD NEUROLOGY SOCIETY ANNUAL MEETING**

VENUE: Boston, Massachusetts

DATE: 29th Sept-2nd Oct 2021

#### **ESA 35TH ANNUAL SCIENTIFIC MEETING**

VENUE: Hotel Grand Chancellor, Hobart and ONLINE

DATE: 2nd – 4th November 2021

#### **14TH INTERNATIONAL CONGRESS OF INBORN ERRORS OF METABOLISM 2021**

VENUE: Hilton Hotel, Sydney and ONLINE

DATE: 21st – 23rd November 2021

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

VENUE: Chicago, Illinois

DATE: 3rd – 7th December 2021

#### **7 TH INTERNATIONAL SYMPOSIUM ON PAEDIATRIC MOVEMENT DISORDERS**

VENUE: Barcelona, Spain

DATE: 9th – 11th February 2022

#### **UPDATED-16th AOCCN**

VENUE: Shangri-La, Bangkok. Thailand

DATE: 24th – 26th March 2022

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>

#### **AMERICAN ACADEMY OF NEUROLOGY, 74TH ANNUAL MEETING**

VENUE: Seattle, WA

DATE: 2nd – 7th April 2022

## EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY

14th EPNS Congress

Venue: Glasgow, UK

Date: 28th April – 2nd May 2022

### EDUCATION AND TRAINING OPPORTUNITIES

#### **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 first boutique style Australian course PET1 was successfully delivered in May and was well received.

PET1 will be repeated with PET3 at the end of October. There is now a long waiting list for courses, and unfortunately currently only able to run a single small group from Sydney due to limited faculty availability. It is hoped that virtual faculty training will become available to allow us to meet the demand for course as soon as possible.

For more details, please contact Simone at [simone.ardernholmes@health.nsw.gov.au](mailto:simone.ardernholmes@health.nsw.gov.au)

#### **ANZCNS CLINICAL CASE FORUM 2021**

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: **Nicola Fearn**

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 2 months; the next will be in October. 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)) 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

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