

Dear ANZCNS Members,

WELCOME TO THE ANZCNS E-NEWSLETTER FOR DECEMBER 2020.

Firstly, a very happy holidays to everyone. This year has been difficult for many and I'm sure everyone is looking forward to a much-needed break. Just a few announcements for this newsletter.

For 2021, I will endeavour to send out a newsletter every 2 months, starting from February. 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](#).

The ANZCNS board has decided to alter the subscription fees for 2020/2021 to reflect the impact of the COVID 19 pandemic on our organisation's educational activities, in particular the need to cancel the 2020 Melbourne annual scientific meeting. Please note that the below fees are only for 2020/2021 and will be reviewed again the following year.

Ordinary membership \$250 and Overseas membership \$140. This is a 30% reduction from usual fees.

Trainees and Associate membership to be waived for 2020/2021 cycle, however we still ask that you renew your subscriptions so your record is up to date.

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.

WHAT YOUR BOARD HAS BEEN UP TO OVER THE LAST 2 YEARS

The Society has had significant achievements in three priority areas from our 2018-2020 organisational strategic plan:

1. Membership

- advertising of trainee positions via the ANZCNS newsletter

2. Learning and development

- holding regular ANZCNS Clinical Case Forums, with improved attendance
- running successful annual scientific meetings in Perth and Sydney
- making significant progress in the organisation of BPNA PET courses with the establishment of a national steering committee, allocation of seed funding and drawing up of an MOU

3. Governance and systems

- allocating officeholder roles among the directors
- convening a strategic planning day to identify priority projects aligned with the strategic plan to be funded by the Society. Priority options will be presented at the AGM and feedback will be sought from the general membership via a survey.
- commencement of work on an organisational financial plan, that includes 5 year financial projections, which aims to achieve a sound financial position to facilitate funding of priority projects, selected by the general membership over the next 3 years.

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]. If you have questions about this communication, please contact Richard Leventer Richard.Leventer@rch.org.au or Eloise Uebergang eloise.uebergang@mcri.edu.au. For specific questions related to Aspa's clinical program, please email clinicaltrials@aspatx.com.

RACP ANNOUNCEMENT

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>

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.

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

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 – ANZAN EEG COURSE

VENUE: Virtual

DATE: 13th and 14th February 2021

INTERNATIONAL PAEDIATRIC STROKE ORGANISATION

VENUE: Vienna, Austria

DATE: 18th-20th July 2021

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:

<https://www.aocnat.org/membership.php>

16th AOCCN

Venue: Shangri-La, Bangkok. Thailand

Date: 5th-7th August 2021

ESA 35th ASM

Venue: Hotel Grand Chancellor Hobart

Date: 2nd-4th November 2021

EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY-POSTPONED to 2022

14th EPNS Congress

Venue: Glasgow, UK

Date: 28 April – 2 May 2022

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://aspnr.org/awards/international-pediatric-neuroradiology-teaching-network/>

ANZCNS CLINICAL CASE FORUMS 2021

19th January - Royal Children's Hospital Melbourne

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. Remember to wash your hands with soap and water and practice physical distancing.

Kind regards,
Hooi Ling and Lejla

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