

Dear Members,

We hope this email finds everyone well. Attached is the May 2020 newsletter. A few new items of interest including a research fellow position with Prof Dale, PBAC resubmission for nusinersen in pre-symptomatic SMA and some teaching materials. Prof Farrar is still looking for participants for a research study in Spinal Muscular Atrophy Care and would appreciate if members could take a 15-20minutes survey. Please send Lejla or myself any items that you think could be of interest to other members and we will add it to the newsletter in July 2020. Happy reading.

If 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. [Membership for 2019/2020 is now overdue.](#)

ANZCNS 9TH ANNUAL SCIENTIFIC MEETING UPDATE

The 9th Annual Scientific Meeting of the ANZCNS for 2020 has been postponed.

Tentative date is 1st-3rd September 2021 in Melbourne at the Pulman Albert Park. The annual ANZCNS AGM will go ahead by video-link. Details will be sent closer to the date but likely via gotomeeting.

ANNOUNCEMENTS

NEW-RESEARCH PAEDIATRIC NEUROLOGY FELLOWSHIP

There is a full time research fellowship opportunity for 2021 at Children's hospital at Westmead in Sydney working with Professor Russell Dale and Dr Shekeeb Mohammad. The fellowship will involve clinical research data collection and engagement with biological specimen collection and laboratory biomarker development. The fellow would get substantial exposure and education in movement disorders, Tourette syndrome, neuropsychiatry and neuroimmunology. The fellow would become competent in research methodology, assessment and management of movement and psychiatric disorders. The fellow would be involved in Biomarker development in immunology and CSF metabolomics and proteomics. Opportunities exist as a one year fellowship or if genuinely interested, a longer PhD opportunity.

For more details, please contact Prof Dale: Russell.dale@health.nsw.gov.au

NEW-NUSINERSEN PBAC RESUBMISSION FOR THE TREATMENT OF PATIENTS WITH PRE-SYMPOMATIC SMA

PBAC Agenda is now available and Consumer Comments welcomed

"Your comments are welcome whether you are a patient, carer, member of the public, health professional or member of a consumer interest group. The company applying for subsidy under the PBS Scheme has already provided the PBAC with detailed clinical and economic data in support of the application. You are welcome to provide comments, for consideration by the PBAC, from a personal or group perspective on the impact of the condition addressed in the application."

Consumer Comments Submission Form link is:

https://www1.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

NEW-INTERNATIONAL PEDIATRIC NEURORADIOLOGY TEACHING NETWORK

The ASPNR offers FREE weekly lecture series in the field of pediatric 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/>

NEW-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>

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

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.

PKAN TRIAL IN AUSTRALIA

Seeking patients for a treatment trial in PKAN, based in Melbourne in collaboration with Susan Hayflick (OHSU, Oregon). We aim to commence this oral therapy trial in early 2020.

Please contact Rick Leventer for further details - richard.leventer@rch.org.au

UPCOMING CONFERENCES

INTERNATIONAL PAEDIATRIC STROKE ORGANISATION-POSTPONED

INTERNATIONAL CHILD NEUROLOGY ASSOCIATION-Still going ahead and early registration late May to June.

All members are encouraged to obtain full membership of ICNA. Membership is free and can be obtained via the following link <http://icnapedia.formbin.com/forms/join>

2020 CNS-ICNA Conjoint Meeting, 19-23 October 2020, Marriott marquis, San Diego
Abstract submission is now closed.

EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY

14th EPNS Congress, 1-5 June 2021
Venue: Glasgow, UK

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>

16th AOCCN in Bangkok, Thailand - 3rd-8th, AUG, 2021

EDUCATION AND TRAINING OPPORTUNITIES

ANZCNS CLINICAL CASE FORUMS 2020

CCF recommencing soon.

Because of popular demand, the monthly CCF is back.

Dates and presenting sites are below.

We kindly request the presenting site to inform us as soon as possible if they are unable to present on a particular date and need to swap.

26th May - Sydney Children's Hospital

23rd June - Perth Children's Hospital

28th July - Royal Children's Hospital Melbourne (2)

25th August - John Hunter Children's Hospital, Newcastle

22nd September - The Children's Hospital at Westmead (2)

27th October - Queensland Children's Hospital (2)

24th November - Monash Medical Centre

15th December - Sydney Children's Hospital (2)

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 social distancing.

Kind regards,
Hooi Ling and Lejla