

# rare

# Kids



Australian Paediatric Surveillance Unit **NEWSLETTER** NOVEMBER 2015

## We can now be found on Social Media

We really appreciate people liking us and keeping us in their social media feed. Like and follow us on Facebook and Twitter to keep up to date with current news and developments in the APSU.



[facebook.com/APSU.Australia](https://facebook.com/APSU.Australia)



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## New Studies Added to the Card

### Chronic Fatigue Syndrome (CFS)

Chronic fatigue syndrome (CFS) is characterised by significant fatigue accompanied by a range of symptoms including; pain, cognitive, sleep, and immune symptoms. Epidemiological studies suggest CFS is far less common in children and adolescents compared with adults.

This study aims to investigate the incidence of CFS in children and adolescents using the Australian Modification of the CDC criteria as developed by the working group under the auspices of the Royal Australasian College of Physicians.

This study, led by Dr Sarah Knight, aims to describe clinical and demographic features and treatments/interventions for CFS currently used in Australia. Please report all cases newly diagnosed from April 2015 according to the protocol and questionnaire distributed to you and available on the APSU website [www.apsu.org.au](http://www.apsu.org.au).

### 22q11.2 Deletion Syndrome (22q)

This study commenced in July and is the first in Australia to investigate the prevalence and incidence of 22q11.2 deletion syndrome and the associated health care needs of children. The current study will establish a cohort of diagnosed cases and follow them over time to provide longitudinal data on health care needs for people with 22q11.2 Deletion Syndrome.

Please report only newly diagnosed cases of children < 16 years of age with genetically confirmed 22q11.2 deletion syndrome, whom you have seen since July 2015 and that you have not previously reported to the APSU.

## Save the Date — Rare Disease Day Workshop 2016

Sunday 28th February 2016

- ◆ Family workshop

Monday 29th March 2016

- ◆ Child Health Professionals Workshop

## New Studies - to be added in the near future

- ◆ Early Onset Eating Disorders (EOED)
- ◆ Neonatal Stroke

## Recent publications

Take a moment to read a great publication by Yvonne Zurynski and Elizabeth Elliott in the September edition of The Australian Family Physician "[Rare Diseases are a 'Common' problem for Clinicians](#)" Elliott, E. and Y. Zurynski (2015). "Rare diseases are a 'common' problem for clinicians." Aust Fam Physician 44(9): 630-633.

McGillivray A, Polverino J, Badawi N, Evans N. *Prospective Surveillance of Extreme Neonatal Hyperbilirubinemia in Australia*. The Journal of pediatrics. 2015. J Pediatr. 2015 Oct 15. pii: S0022-3476(15)00981-6.

Raynes-Greenow, C., Polis, S., Elliott, E., Hardikar, W., Kesson, A., Kaldor, J., & Jones, C. A. (2015). *Childhood hepatitis C virus infection: An Australian national surveillance study of incident cases over five years*. J Paediatr Child Health, 51(11): 1115-1120.

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## Completed Studies / Study Progress

### Severe Complications of Influenza

This study was once again conducted from July to September 2015 and data has now been analysed. Thank you to all clinicians for contributing cases. Key findings were as follows:-

There were 86 cases reported of children admitted to hospital with serious complications of influenza (59 Flu B; 27 Flu A) including seizures, encephalitis, pneumonia, viral/bacterial co-infections and rhabdomyolysis. Twenty-six (30%) children required an ICU admission and three children died.

Of the 86 children, 58% were previously healthy, while 42% had chronic pre-disposing conditions including asthma, chronic lung disease, cerebral palsy and epilepsy. Only 4 children were vaccinated for influenza within the last 12 months. Children with chronic predisposing conditions are recommended and funded for annual influenza vaccination under the National Immunisation Program and should be vaccinated each year to avoid hospital and ICU admissions.

(<http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/immunise-influenza#flu>).

### APSU ARC Linkage Project Grant Update

**“Paediatricians Caring for Children with Rare Diseases: Survey of current knowledge, practice and future educational needs.”** (Investigators :A/Prof Yvonne Zurynski, Dr Aranzazu (Arancha) Gonzalez, Prof Helen Leonard, Prof Elizabeth Elliott, Prof John Christodoulou)

This study was undertaken by Dr Arancha Gonzalez as an RACP Advanced Trainee Project under the supervision of Yvonne Zurynski and Elizabeth Elliott. We have just heard that Arancha’s project was well received by the examiners and she has now qualified for her FRACP. Congratulations Arancha!

679 APSU clinicians were randomly selected to participate in this important survey which assessed the current awareness of rare diseases, need for information about referral pathways, diagnostic and clinical services accessed for rare disease patients, needs for educational materials and opportunities, and the preferred way to deliver these.

242 paediatricians (35.6%) completed the survey. The majority (89%) of paediatricians underestimated the aggregate prevalence of rare diseases and many were unaware of web-based information resources specific to rare diseases. Most paediatricians were open to up-skilling in rare diseases and in how to use existing web based resources to optimise their care of children with rare diseases. Approximately 75% paediatricians used smartphone/tablet apps in clinical practice, mostly those aged <50 years and females, and many indicated that they would use online educational modules if these were offered.



*Dr Arancha Gonzalez drawing the winners*

Based on the results, recommendations have been made to develop educational modules about rare diseases and a centralised web portal with links to other evidence-based resources, both practical and educational.

**A big thank you to APSU contributors who responded and completed the survey.**

Those who completed the survey went into a draw to win a \$50 Myer gift voucher.

**Congratulations to our winners:**

Dr Gerry Santos, Dr Carolyn Leerdam, Professor Keith Grimwood, Dr Anna Hackett and Dr Michael Rosier.

## Achievements

**Dr Tracey Tsang** (Senior Research Fellow)

- ◆ Best poster presentation at the 5th International Drug Abuse Research Society Conference & 4th Asia-Pacific Society for Alcohol & Addiction Research
- ◆ Foundation for Alcohol Research & Education (FARE) Scholarship to cover conference registration costs for the 5th International Drug Abuse Research Society Conference & 4th Asia-Pacific Society for Alcohol & Addiction Research

**Mr Troy Dalkeith** (PhD Candidate)

- ◆ Cerebral Palsy Alliance Prize for Excellent Student Presentation at the Sydney Medical School Discipline of Paediatrics and Child Health Postgraduate Research Student Conference 2015

## Congratulations to the BPSU – 30 Years!

Congratulations to the British Paediatric Surveillance Unit on their 30th Anniversary! BPSU has been a leader in paediatric surveillance since 1986 and all 10 currently active units in the International Network of Paediatric Surveillance Units (INOPSU; [www.inopsu.com](http://www.inopsu.com)) are modelled on the highly successful BPSU system. BPSU will celebrate this important milestone by holding a [Rare Diseases Conference in York, UK, 23 February 2016](#).

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## APSU Scientific Review Panel Expression of Interest

The APSU is seeking expressions of interest from experienced paediatricians/researchers with an interest in rare childhood conditions to join its Scientific Review Panel (SRP). We need three new members, preferably from South Australia, Victoria and Queensland.

The APSU is a national resource which facilitates surveillance and research into rare childhood conditions including rare infectious diseases, rare genetic conditions, rare injuries and other rare conditions or rare complications of more common conditions.

The SRP reviews applications from groups of investigators who want to conduct surveillance using the APSU system. The committee meets 3 times per year via teleconference. For more on the APSU please visit our website [www.apsu.org.au](http://www.apsu.org.au)

If you are interested in joining the SRP, please provide a **brief** CV listing your qualifications, experience and key relevant publications and tell us why you're interested in serving on the SRP. Send your expression of interest to: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au). For any queries please contact the APSU on 02 9845 3005 or contact Dr Marie Deverell ([marie.deverell@health.nsw.gov.au](mailto:marie.deverell@health.nsw.gov.au) or 02 9845 2200).

## Upcoming Events

### Save the Date: Rare Disease Workshop (Sunday 28th February and Monday 29th February 2016)

The APSU will be hosting a two day workshop at The Kids Research Institute, The Children's Hospital at Westmead. The Sunday program will be for families and the Monday program will target clinicians. Keep an eye out for further information by email, and also on our [Facebook](#) and [Twitter](#) pages.

### RACP Congress 2016: APSU Session 17th May 1:30–3:00pm

The session will be focussed on rare childhood injuries:

- ◆ Ingestion or insertion of alkaline batteries
- ◆ Female genital mutilation and cutting in children resident in Australia
- ◆ Subdural haematoma in children aged < 2 years – deciding on the cause of injury
- ◆ Seatbelt safety – are we there yet?

## ASPU Staff Changes

After 10 years of service with the APSU, we would like to thank and farewell **Ingrid Charters** (Administration Officer). Ingrid has moved to take on the position of Administration Officer at the National Centre for Immunisation Research & Surveillance (NCIRS) within The Kids Research Institute, Westmead. We wish Ingrid all the best on her future endeavours.

**RedCap Online Reporting** Clinicians are now able to complete most case report forms online through our data capture management system (RedCap). Simply click on the link provided in the monthly report card email to complete the form. Links to the current APSU protocols and case report forms can be found in the monthly email report card and are also available for download on the APSU website. If you have any difficulties accessing the links or would like more information about completing the forms online, please contact us.

**Still returning the yellow card by post?** If you are one of the remaining 108 clinicians out of 1600 still receiving the yellow report card we would like to make responding easier for you.

**Not currently an APSU Contributor?** We would very much like you to become a member of the APSU and to contribute data to support our unique national surveillance effort.

**Changed your contact details?** Please let us know your new details.

To start responding via email, to join the APSU or to notify us of your changed contact details please contact us on: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

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