



# rare Kids

Australian Paediatric Surveillance Unit **NEWSLETTER**

## December 2016

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### New Studies in development:

- Severe Injury related to Disc Battery ingestion or insertion
- Neonatal Stroke in Children < 2 years of age

Welcome to the December 2016 edition of the APSU's Rare Kids newsletter. We hope that you will find the newsletter interesting and informative.

Feel free to provide us with feedback — you can contact us at [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

## Congratulations

Congratulations to Professor Elizabeth Elliott, Director of the APSU, who has been awarded the prestigious **Howard Williams Medal** for 2017.

Each year at the RACP Congress the Paediatrics & Child Health Division officially acknowledges a person who has made an outstanding contribution to Paediatrics and Child Health in Australia or New Zealand. Elizabeth will deliver the Howard Williams oration at the RACP Congress 8<sup>th</sup>–10<sup>th</sup> May 2017 in Melbourne .

## Thank You Professor Nigel Dickson!

The Australian Paediatric Surveillance Unit would like to extend a very warm and heartfelt Thank You to Professor Nigel Dickson.

Nigel has been a long standing member of the APSU Scientific Review Panel. His contribution to the APSU has been extremely helpful and valued by all who have served on the APSU over the last 20 years. Nigel will be greatly missed by all of us at the APSU. Best wishes in your retirement.



Prof Nigel Dickson

## Recent Publications

Mehr, S., Allen, R., Boros, C., Adib, N., Kakakios, A., Turner, P. J., Rogers, M., Zurynski, Y. & Singh-Grewal, D. 2016. Cryopyrin-associated periodic syndrome in Australian children and adults: Epidemiological, clinical and treatment characteristics. *J Paediatr Child Health*, 52, 889-95.

Lutz, T. L., Elliott, E. J. & Jeffery, H. E. (2016). Sudden unexplained early neonatal death or collapse: a national surveillance study. *Pediatr Res*, 80, 493-8.

## Recent Abstracts Published from RACP Congress 2016

Zurynski Y, Ridley G, Phu A, Booy R, Elliott E. Influenza related complications and deaths in Australian children: seasonal surveillance 2008–2015. *Journal of Paediatrics and Child Health*. 2016;52:13-4.

Zimmet M, Phu A, Zurynski Y, Watkins R, Bower C, Elliott E, APSU Project Reference Group. Fetal alcohol spectrum disorders in Australia: provisional findings of prospective national case surveillance. *Journal of Paediatrics and Child Health*. 2016;52:9-10.

Gonzalez A, Zurynski Y, Phu A, Deverell M, Elliott E. Paediatricians caring for children with rare diseases: survey of current knowledge, practice and future educational needs. *Journal of Paediatrics and Child Health*. 2016;52:12.

Deverell M, Phu A, Elliott E, Clarke N, Young H, Sampo H, Zurynski Y. Moving from paediatric to adult health services: transition experiences of young people with neuromuscular disorders. *Journal of Paediatrics and Child Health*. 2016;52:14.

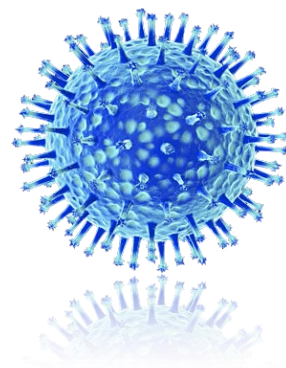
## Completed Studies / Study Progress

### Severe Complications of Influenza

Thank you to all clinicians for once again contributing cases of Severe Complications of Influenza admitted to hospital during July — September 2016. This year was a quiet season compared last year (86 case reported in 2015 with 69% Flu B).

28 cases were reported of influenza (27 Flu A and 1 Flu B) complications of 2016 including pneumonia, thrombocytopenia, bacterial co-infections and seizures. Seventeen (61%) children required ICU admission, no child died.

Of the 28 children, 43% were previously healthy, while 57% had chronic pre-disposing conditions including asthma (14%), blood related disorders (11%) and prematurity (11%). Only one child was 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>



### Microcephaly Update

To date the APSU has received a total of 11 confirmed cases meeting the reporting criteria.

Please report any child < 12 months of age with microcephaly when: Occipito-Frontal head Circumference (OFC) is more than **two standard deviations or <3rd percentile below the mean** for gestation\*, age and gender according to standard growth charts (CDC Growth Charts— [CDC for Boys](#); [CDC for Girls](#) ), presenting to you in the last month and whom you have not previously reported.

For Example: Any Male born at term with a OFC <32.1cm or Female born at term with a OFC <31.7cm would meet the criteria

\* use Fenton growth charts to adjust for gestational age/prematurity: [Fenton Chart for Boys](#); [Fenton Chart for Girls](#).

Please continue to report any new cases through the APSU reporting channel. Should you have any questions regarding this study, please feel free to write to us at: [SCHN-APSU@health.nsw.gov.au](mailto:SCHN-APSU@health.nsw.gov.au)

**The Polio Expert Panel encourages all paediatricians to continue reporting all cases of AFP to the APSU**

### Keeping Australia Polio Free — Keep reporting cases of AFP

High quality acute flaccid paralysis (AFP) surveillance is essential to maintain polio-free status certification of Australia by the WHO. The WHO indicators of surveillance performance include a target annualised non-polio AFP rate of >1/100 000 children under 15 years of age. Two stool samples for testing to exclude polio virus should be collected within 14 days of the onset of paralysis and sent to the National Polio Reference Laboratory .

More details at: [www.vidrl.org.au/laboratories/poliovirus-reference/specimen-referral](http://www.vidrl.org.au/laboratories/poliovirus-reference/specimen-referral)

Please do not hesitate to contact us if you have any questions about this surveillance

## Recent Events

### HGSA

#### Hobart Tasmania, 6-9 August 2016



**Integrating Genomics into Healthcare**

6-9 August 2016 • HGSA 40th Annual Scientific Meeting HOBART, TASMANIA

This year the Human Genetics Society of Australasia (HGSA) Annual Scientific Meeting was held at the Hotel Grand Chancellor in Hobart, Tasmania, 6-9 August 2016. The theme for the conference was “Integrating Genomics into Healthcare”.

A/Prof Yvonne Zurynski was invited to present at a plenary session on Rare Disease Registries organised by Rare Voices Australia [www.rarevoices.org.au](http://www.rarevoices.org.au)

## Recent Events

### 28th International Congress of Paediatrics Vancouver, Canada, 17-22 August 2016



The IPA is the largest global paediatric congress which occurs every 3 years.

The Congress included presentations from the APSU and a satellite meeting of the [International Network of Paediatric Surveillance Units \(INoPSU\)](#) on the 16th of August 2016. Six of the 10 international units were in attendance and international paediatric surveillance data was presented. For more information: [www.ipa2016.com](http://www.ipa2016.com)

Associate Professor Yvonne Zurynski was recipient of the inaugural Danielle Grenier Award Recognizing Excellence in the Study of Rare Paediatric Diseases Using Surveillance Research from the International Network of Paediatric Surveillance Units.

The APSU was pleased to present the following:

- How to use surveillance data to improve practice and care, *Prof Elizabeth Elliott*
- Influenza Related Complications and Deaths in Australian Children: Seasonal Surveillance 2008—2015, *A/Prof Yvonne Zurynski*

The APSU also presented several posters:

- Female Genital Mutilation/Cutting in Australia: Paediatricians' Knowledge, Attitudes and Practice, *Prof Elizabeth Elliott*
- Paediatricians caring for children with rare diseases: Survey of current knowledge, practice and future educational needs, *A/Prof Yvonne Zurynski*
- APSU FASD provisional findings, *Dr Marcel Zimmet*
- Moving from Paediatric to Adult Health Services: Experiences of Adolescents with Neuromuscular Disorders, *Dr Marie Deverell presented by A/Prof Yvonne Zurynski (e-poster)*



*A/Prof Yvonne Zurynski*

### Professor Elizabeth Elliott inducted into the Australian Academy of Health and Medical Science

Professor Elizabeth Elliott, the founder of the Australian Paediatric Surveillance Unit was inducted into the Fellowship of the Australian Academy of Health and Medical Sciences. Professor Elliott is a consultant paediatrician for SCHN based at The Children's Hospital at Westmead's Clinical School. She is also a distinguished Professor of Paediatrics and Child Health at the University of Sydney and holds an NHMRC Practitioner Fellowship.

With an international reputation in medical research, education and advocacy, Professor Elliott is a consultant for the Australian Human Rights Commission, the World Health Organization and a Member of the Order of Australia. She has brought attention to a number of important child health issues including Fetal Alcohol Spectrum Disorders, vaccine-preventable and other infectious diseases as well as issues affecting children in Indigenous communities and children in detention.

Her recognition by the Australian Academy of Health and Medical Sciences is well deserved and she joins two other members of the Children's Hospital Westmead Clinical School who are also Fellows of the Academy - Professor Ian Alexander and Professor Louise Baur.



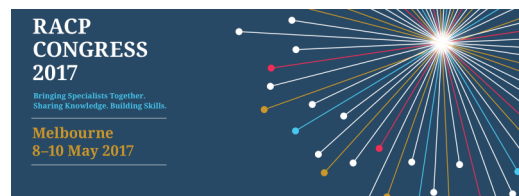
*Prof Elizabeth Elliott*



## Upcoming Events

### RACP Congress, Melbourne

8th May 2017 — 10 May 2017



The new shared interest RACP Congress 2017 is an opportunity for you to:

- learn about medical breakthroughs
- hear the latest clinical updates
- join the conversations on the 'big issues' that are relevant to all physicians; obesity, disability, ageing and end of life issues
- attend high energy, cross-disciplinary think tanks
- network with global thinkers and healthcare leaders, socialise with peers and forge new professional ties
- getaway and explore all that Melbourne, Victoria, Australia has to offer

[RACP Congress 2017— website & registration](#)



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#### Disclaimer

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**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 95 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)