

# rare Kids



Australian Paediatric Surveillance Unit NEWSLETTER

July 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 July 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)

## ***Upcoming Surveillance Studies***

### ***Microcephaly***

The APSU has been invited by the Department of Health to undertake surveillance for Microcephaly due to all causes in children aged <12 months.

This study will provide the first national data on the background rates and the causes of microcephaly in Australia. Microcephaly is of current interest due to the proven relationship between maternal Zika virus infection and microcephaly in children.

#### ***Case Definition***

Please report any child < 12 months of age with microcephaly when the Occipito-Frontal Head Circumference is more than **two standard deviations (<3<sup>rd</sup> percentile) below the mean** for age and gender according to standard growth charts\* who presented to you in the last month and whom you have not previously reported.

\*The WHO recommends the Intergrowth Charts (<https://intergrowth21.tghn.org/>) which allow for adjustment for gestational age and are based on a wide range of ethnicities. The Intergrowth calculator can be found at <http://intergrowth21.ndog.ox.ac.uk/en/ManualEntry>.

NB: It is advised all children have OFC measured at birth and as part of routine child health checks.

The study protocol and case report forms will be available on the [APSU website](#) from end of June 2016.

### ***Recent Publications***

Zurynski, Y., Sureshkumar, P., Phu, A., & Elliott, E. (2015). Female genital mutilation and cutting: a systematic literature review of health professionals' knowledge, attitudes and clinical practice. *BMC Int Health Hum Rights*, 15(1), 32.

Sureshkumar, P., Zurynski, Y., Moloney, S., Raman, S., Varol, N., & Elliott, E. J. (2016). Female genital mutilation: Survey of paediatricians' knowledge, attitudes and practice. *Child Abuse Negl*, 55, 1-9.

Durkan, A. M., Kim, S., Craig, J., & Elliott, E. (2016). The long-term outcomes of atypical haemolytic uraemic syndrome: a national surveillance study. *Arch Dis Child*, 101(4), 387-391.

Li-Kim-Moy, J., Dastouri, F., Rashid, H., Khandaker, G., Kesson, A., McCaskill, M., Wood, N., Jones, C., Zurynski, Y., MacArtney, K., Elliott, E.J., Booy, R. Utility of early influenza diagnosis through point-of-care testing in children presenting to an emergency department (2016) *Journal of Paediatrics and Child Health*, 52 (4), pp. 422-429.

Desai, S., Smith, T., Thorley, B.R., Grenier, D., Dickson, N., Altpeter, E., Sabbe, M., Elliott, E., Zurynski, Y., Rudin, C., Bernet-Büttiker, V., Laubscher, B., Simonetti, G., Barbe, K.P., Mäusezahl-Feuz, M., Beeli-Von Büren, D. Performance of acute flaccid paralysis surveillance compared with World Health Organization standards (2016) *Journal of Paediatrics and Child Health*, 51 (2), pp. 209-214.

Hime, N.J., Zurynski, Y., Fitzgerald, D., Selvadurai, H., Phu, A., Deverell, M., Elliott, E.J., Jaffe, A. Childhood interstitial lung disease: A systematic review (2015) *Pediatric Pulmonology*, 50 (12), pp. 1383-1392.

## Recent Studies added to the Report Card

### Severe Complications of Influenza

Once again the APSU will be conducting surveillance for severe complications of influenza.

Please note that surveillance has started earlier than previous years, please start reporting cases to the APSU now.

This year the study will run from the 1<sup>st</sup> June 2016 until the 30<sup>th</sup> September 2016.

Please notify any cases to the APSU as soon as possible during the study period.

Please use this *secure web link* to an on-line case report form:

[surveys.sydney.edu.au/surveys/?s=iCRQVoMwAg](http://surveys.sydney.edu.au/surveys/?s=iCRQVoMwAg)

or complete and fax (02 9845 3082) a paper form which can be downloaded from our website:

[apsu.org.au/assets/current-studies/SevereInfluenza-QuestLetter-2016-APSU.pdf](http://apsu.org.au/assets/current-studies/SevereInfluenza-QuestLetter-2016-APSU.pdf)

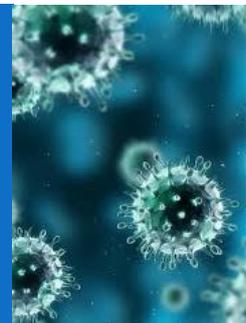
Please report any child aged < 15 years with laboratory confirmed influenza AND admitted to hospital AND who have at least one of the following complications:

- Pneumonia (Confirmed on X-ray or microbiology)
- Oxygen requirement
- Mechanical ventilation
- Laboratory proven secondary bacterial co infection; Bacteraemia; Septicaemia;
- Encephalitis / encephalopathy
- Seizures (including simple febrile seizure, prolonged or focal seizure or status epilepticus)
- Transverse myelitis
- Polyneuritis/ mononeuritis
- Guillain-Barré syndrome
- Reye Syndrome
- Myocarditis; Pericarditis; Cardiomyopathy
- Rhabdomyolysis
- Purpura fulminans
- Disseminated coagulopathy
- Shock (requiring >40 ml/kg fluid resuscitation)
- Acute renal failure
- Death, including death at presentation to hospital

Since 2008 APSU has described 474 cases of severe complications of influenza including 25 deaths in children aged <15 years.

174 (36.7%) had pre-disposing chronic conditions.

Such children are recommended and funded for annual flu vaccination but only 18 (10%) had been vaccinated.



For recommendations: ([www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/immunise-influenza#flu](http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/immunise-influenza#flu)).

### Early Onset Eating Disorder

Anorexia nervosa is a common chronic illness affecting adolescent females. It has been proposed that the age of onset of anorexia nervosa is decreasing. However, there is wide variation in the few available estimates of incidence of eating disorders in children under 13 years of age.

This study is led by Dr Sloane Madden and Dr Anne Morris, we hope this study will help us estimate the incidence and clinical features of early onset eating disorder in Australia and provide comparison with data collected in a previous similar study conducted in 2002-2005.

Please report any child aged **from 5 to 13 years inclusive** with a newly diagnosed eating disorder defined as:

*Determined food avoidance AND weight loss or a significantly low body weight (less than minimally normal) in the context of age, gender, developmental trajectory and physical health.*

## 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 and two stool samples for each case need to be sent to the National Polio Reference Laboratory for testing to exclude polio virus.

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

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

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

## Recent Events

### *Female Genital Mutilation is Everyone's Business, Australian Human Rights Commission, Sydney, 29th April 2016*



(L to R) A/Prof Yvonne Zurynski, Emeritus Professor Gillian Triggs, Juliana Nkrumah AM, Mmaskepe Sejoie, Professor Elizabeth Elliott AM

On Friday the 29<sup>th</sup> April the Australian Paediatric Surveillance Unit and NO FGM Australia co-hosted its first Australian conference on Female Genital Mutilation (FGM) at the Australian Human Rights Commission in Sydney.

The day included stories from survivors of FGM, presentations on the human rights perspective, child protection perspective, legal implications of FGM, the latest in Australian medical research on FGM in children, educational issues, community initiatives to address FGM and FGM prevention.

Thank you to all the speakers and delegates who attended and made the day a great success.

Presentations can be found on the [ASPU website](#) Photos from the day can be seen on the [ASPU Face-book page](#)

### *RACP Congress: Evolve Educate Engage, Adelaide 16-18 May, 2016*

This year saw the reintroduction of a separate Paediatric Stream and a Paediatric dinner to the RACP Congress.

The APSU was pleased to host an exciting session on child injuries which included the following presentations:

- Subdural Haematoma in children < 2 years—deciding the cause of injury, *Dr Susan Marks*
- Female Genital Mutilation and Cutting in children resident in Australia, *Professor Elizabeth Elliott*
- Serious Injuries due to Ingested or Inserted Batteries in Children, *Dr Ruth Barker*
- Are We There Yet? Seatbelt related injuries in children ages < 13 years, *A/Prof Yvonne Zurynski*

Our session was very expertly chaired by A/Prof Harriet Hiscock – thank you Harriet!

In addition to the APSU session, many abstracts reporting APSU data were accepted as free papers.

It was a great opportunity to present results to which all APSU paediatricians have contributed:

- Fetal Alcohol Spectrum Disorders in Australia: provisional findings of prospective national case surveillance, *Dr Marcel Zimmel*
- Influenza Related Complications and Deaths in Australian Children: seasonal surveillance 2008-2015, *A/Prof Yvonne Zurynski*
- Moving from Paediatric to Adult Health Services: transition experiences of young people with Neuromuscular Disorders, *A/Prof Yvonne Zurynski*
- An Australian National Prospective Study of the Incidence of Juvenile Onset Recurrent Respiratory Papillomatosis, *A/Prof Daniel Novakovic*
- Paediatricians Caring for Children with Rare Diseases: survey of current knowledge, practice and future educational needs, *Dr Arancha Gonzalez*



Dr Arancha Gonzalez presenting at RACP Congress

## Recently Published Encephalitis Guidelines for Australia and New Zealand

A comprehensive guideline for the investigation and management of encephalitis in Australia and New Zealand has just been published in the *Internal Medicine Journal (IMJ)* [onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1445-5994](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1445-5994)

Encephalitis is a challenging condition associated with mortality in up to 10% of cases and a potential for significant neurological morbidity in survivors. Infectious causes of encephalitis include vaccine preventable diseases, zoonoses and emerging infectious diseases in our region e.g. measles, varicella, influenza, Hendra virus, Australian bat lyssa-virus, Murray Valley encephalitis virus, Japanese encephalitis virus, enterovirus 71, Dengue and Nipah virus.

The development of the guideline has been led by the Australasian Society for Infectious Diseases (ASID) Clinical Research Network chaired by Professor Cheryl Jones. Membership of this group includes ASID members with an interest in encephalitis across Australia and New Zealand, and non-ASID members with expertise in public health and neurology. In addition to ASID endorsement, the guideline was reviewed, contributed to and endorsed by the Australasian College of Emergency Medicine (ACEM), Australian and New Zealand Association of Neurologists (ANZAN) and the Public Health Association of Australia (PHAA).

Please contact Dr Britton for further information ([philip.britton@health.nsw.gov.au](mailto:philip.britton@health.nsw.gov.au))

## Upcoming Events

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

Human Genetics Society of Australasia (HGSA) Annual Scientific Meeting to be held at the Hotel Grand Chancellor in Hobart, Tasmania, 6-9 August 2016. The theme for the conference is "Integrating Genomics into Healthcare". A/Prof Yvonne Zurynski has been invited to present at a session on Rare Disease Registries organised by Rare Voices Australia [www.rarevoices.org.au](http://www.rarevoices.org.au) For more information: [www.hgsa.org.au/about/40th-annual-scientific-meeting](http://www.hgsa.org.au/about/40th-annual-scientific-meeting)

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

The IPA is the largest global paediatric congress which occurs every 3 years. The Congress will include presentations from the APSU and a satellite meeting of the International Network of Paediatric Surveillance Units (INoPSU) on the 16th of August 2016. At least 6 of the 10 international units will be in attendance and international paediatric surveillance data will be presented. For more information: [www.ipa2016.com](http://www.ipa2016.com)



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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](http://www.apsu.org.au). 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)