



Australian Paediatric Surveillance Unit **NEWSLETTER** December 2013

Changes to Conditions Reported via APSU

New Studies for 2014

FASD—Fetal Alcohol Syndrome Disorders—Commencing January 2014

An APSU study on Fetal Alcohol Syndrome was undertaken in 2001–2004, led by Prof Elizabeth Elliott. Since then, educational materials for health professionals and the wider community have been developed, the NHMRC Alcohol Guidelines have been revised and Australian diagnostic categories and criteria have been drafted.

It is timely to reinstate FASD onto the APSU system in early 2014. Fetal alcohol spectrum disorder (FASD) describes a range of preventable adverse effects that occur as a consequence of in-utero exposure to alcohol including: brain damage, growth failure, birth defects, and problems with development, learning, behaviour and mental health. FASD occurs in all populations of Australia, not only among remote Indigenous communities, and has significant impacts on children, families and health services.

MECP2 Duplication Syndrome—Commencing 2014

MECP2 duplication syndrome is a rare and relatively unknown disorder. Infants may present with developmental delay, hypotonia, and/or dysmorphic facial features while older children may have intellectual disability, progressive lower limb spasticity with or without an episode of regression, epilepsy and recurrent respiratory infections. The diagnosis is confirmed by genetic testing. The APSU study, led by Prof Helen Leonard will provide the first Australian estimates of birth prevalence and incidence of MECP2 duplication syndrome.

The case definitions and criteria for FASD and MECP2 will be distributed to all APSU clinicians and will be posted to the APSU website in early 2014.

Varicella Severe Complications—Study Concluding

This study will finish with the December 2013 report card.

APSU surveillance for Congenital and Neonatal Varicella will continue.

Thank you to everyone who reported cases of severe complications of varicella. This study began in 2006 just after the introduction of the varicella vaccine onto the National Immunisation Program. The number of cases reported to the APSU has steadily declined supporting the effectiveness of vaccination. Data from the Paediatric Active Enhanced Disease Surveillance (PAEDS) which collects all hospitalised cases (rather than severe complications only) also showed a decline in the number of cases admitted.

The investigators will be compiling a final report in the next few months.

APSU FLU Study—2013

Thank you to all our clinicians reporting cases of Severe Complications of Influenza during the 2013 flu season. 13 cases were reported (8 flu B; 5 flu A) and 5 of these children had underlying chronic conditions. Complications included Pneumonia, seizures, myocarditis, pericarditis, encephalopathy and rhabdomyolysis. 5 children had an ICU admission and 2 died. Influenza can result in severe complications and death in children. Vaccination is very important for all eligible children, especially those with chronic conditions.

APSU will once again conduct national surveillance for the severe complications of influenza during the 2014 flu season.

The APSU would like to welcome NEW Staff

- **Amy Phu**—Research Associate, Rare Chronic Diseases project
- **Premala Sureshkumar** - Senior Research Fellow, Female Genital Mutilation
- **Tracey Tsang** - Senior Research Fellow, Foetal Alcohol Spectrum Disorders in remote Aboriginal communities in Fitzroy Valley, WA (The Lililwan Project).

Christmas Closure: 18th Dec—6th Jan

A big thank you to all participating in APSU activities in 2013— we look forward to another exciting year in 2014. Season's Greetings and a Safe and Happy New Year!

Not currently an APSU Contributor?

If you would like to become a member of the surveillance program please contact our office on 02 9845 3005 or apsu@chw.edu.au

Changed your details? Please let us know by contacting the APSU office on 02 9845 3005 or apsu@chw.edu.au

Recent Events



L-R: Dr Jane Ho, A/Prof Yvonne Zurynski, Mr Ryan Murphy, Prof Kate Steinbeck and Ms Annabelle Waller.

A workshop convened by Yvonne Zurynski entitled: Transition, rare diseases and social media – an interactive workshop, was held at the National Youth Health Conference in Perth 13-15 November 2013. Yvonne presented the results of a forum for young people living with rare disease and the challenges they face during this process. We were honoured to have a presentation from Ryan Murphy, a young person living with a rare chronic condition. Ryan spoke about his story of transition from a large tertiary paediatric hospital to a district hospital near his home and the challenges faced by him and his family. Dr Jane Ho, Staff Specialist Trapeze Transition Programme, NSW Health, gave an excellent presentation about the usefulness of social media for engaging young people with transition with health services. Professor Kate Steinbeck provided a comprehensive overview of transition services in NSW. We wish to thank Annabelle Waller, a young person living with a chronic health condition for chairing the workshop together with Kate Steinbeck.

An interactive panel discussion which included the speakers and Lynne Brodie, Manager, NSW Agency for Clinical Innovation, Transition Care Programme enabled exploration of further needs of young people living with chronic disease while transitioning to adult health care.

IPA Congress—Melbourne—24th to 29th August 2013

The International Paediatric Association Congress was a huge success thanks to the mammoth efforts from the Scientific Programme Committee chaired by Prof Elizabeth Elliott and the Organising Committee chaired by Dr Neil Wigg. Results from many APSU studies were presented at the congress and a session dedicated to rare diseases was held with excellent presentations from Elizabeth Elliott (APSU), Yvonne Zurynski (APSU) Danielle Grenier, Director Canadian Paediatric Surveillance Programme, Odile Kremp, Director of Orphanet, Paris, France, Chris Verity, Paediatric Neurologist, Addenbrookes Hospital, Cambridge, UK. The achievements of the APSU over the last 20 years were highlighted and the book entitled Australian Paediatric Surveillance Unit: 20 Years of Research into Rare Diseases was launched.

The International Network of Paediatric Surveillance Units held a pre-conference workshop entitled The Power of International Collaboration to Study Rare Diseases: International Network of Paediatric Surveillance Units. This workshop was convened by Yvonne Zurynski and Elizabeth Elliott. The **International Network of Paediatric Surveillance Units (INOPSU)** showcased the achievements of INOPSU over the last 15 years including impacts of INOPSU results on clinical practice and policy. The INOPSU 15 Year report was launched at this session. Delegates represented 10 different countries participated. Presenters included: Odile Kremp, France; Elizabeth Elliott, Australia; Danielle Grenier, Canada; Christopher Verity, United Kingdom; Sloane Madden, Australia; Yvonne Zurynski, Australia; Nigel Dickson, New Zealand and Matthias Roth, Switzerland. The INOPSU Business Meeting was chaired by the current INOPSU Co-Chairs Yvonne Zurynski (Australia) and Danielle Grenier (Canada) and attended by Daniella Beeli (Switzerland), Alan Emond and Richard Lynn (UK via skype), Nigel Dickson and Barry Taylor (NZ), Rob Rodriguez-Perreira (Netherlands). We were very pleased to host the INOPSU dinner which provided an opportunity for key people from paediatric surveillance units internationally to meet face to face.



We wish to thank The Office of Population Health Genomics, WA Department of Health and the Steve Waugh Foundation for their generous support of the INOPSU workshop and the Rare Disease Session

Photos of APSU and INOPSU Members

Recent Publications

- Noonan S., Zurynski Y.A., Currie B.J., McDonald M., Wheaton G., Nissen M., Curtis N., Isaacs D., Richmond P., Ramsay J.M., Elliott E.J., Carapetis J.R. A national prospective surveillance study of acute rheumatic fever in Australian children. *Pediatric Infectious Disease Journal*. 2013; 22926211.
- Zurynski Y.A, Srikanthan S, Elliott EJ. 20 years of Research into Rare Diseases. 2013; ISBN: 978-0-9923042-0-1
- Zurynski Y, Elliott E. Challenges of transition to adult health services for patients with rare diseases. *MJA* 2013; 198(11):575-576
- Zurynski Y, Deverell M, Elliott E. Forum on Transition to Adult Health Services: Experiences of young people living with rare diseases. <http://www.apsu.org.au/assets/News/Final-Transition-Report-22.07.2013.pdf>
- Esterman E, Lahra M, Zurynski Y, et al. Influenza Infection in infants aged <6months during the H1N1-09 pandemic: A hospital-based case series. *Journal of Paediatrics and Child Health* 2013; 49:635-640
- Zurynski Y, McIntyre P, Booy R, Elliott E, on behalf of the PAEDS Investigators Group. Paediatric Active Enhanced Disease Surveillance: a new surveillance system for Australia. *Journal of Paediatrics and Child Health* 2013; 49:588-94

Australian Paediatric Surveillance Unit

Children's Hospital, Westmead
Cnr Hawkesbury Road and Hainsworth Street,
Westmead, NSW 2145

t 02 9845 3005 f 02 9845 3082

e apsu@chw.edu.au www.apsu.org.au



Disclaimer

The information contained in Rare Kids Newsletter is provided in good faith from sources believed to be accurate and true at the time of publication. The material is provided for general information only and does not constitute professional advice. The APSU does not expect or invite any person to act or rely on any statement, opinion or advice contained herein.