

rare kids



Australian Paediatric Surveillance Unit **NEWSLETTER**

April 2013

Looking forward in 2013

2012 was another great year for the APSU and we look forward to another year of growth and success in 2013. 2013 is one for the history books—it represents our 20th year of active surveillance. To celebrate, the APSU will be producing a 20 year Report and will be showcasing at the International Congress of Paediatrics (ICP).

You are invited to the ICP Congress 24–29 August 2013

The APSU will host a pre-congress workshop for the International Network of Paediatric Surveillance Units (INoPSU) on Saturday the 24th of August where international surveillance results will be showcased and the 15 year INoPSU Report and new website will be launched. A session dedicated to Rare Diseases will be held on Sunday 25th August. We are very excited to welcome Dr Odile Kremp from ORPHANET (www.orpha.net), Professor Chris Verity from Cambridge and Dr Danielle Grenier from the Canadian Paediatric Surveillance Program as guest speakers. We will be launching the APSU 20 Years Report at the Sunday session. Detailed programs will be available on our website www.apsu.org.au in the coming weeks. For more information about the ICP please see <http://www2.kenes.com/ipa/Pages/Home.aspx>

APSU website has a new look. Come and see!

The APSU launched its new look website in December of last year. We believe you will find the new site more straightforward and easier to navigate. We have introduced an events page so you can stay up to date with the latest news and activities in the world of paediatrics. Protocols and questionnaires for all of our studies are available here for download.



If you haven't already, we invite you to head to www.apsu.org.au and have a look around the new site.

We would greatly appreciate any sug-

gestions you may have for the site.

Please email your recommendations to apsu@chw.edu.au

Just a reminder...

The APSU is currently conducting an audit for June–December 2012 report card return. Many of our active contributors will be receiving an email requesting reports for these months.

To ensure that you do not mistake this audit email for the monthly yellow report

APSU Studies

Neonatal and Infant Herpes Simplex Virus Infection – includes children up to 12 months of age! (HSV) infection in a newborn can be devastating with a high risk of death without treatment however there is little information of the burden. We are now collecting data on infant cases up to 12 months of age. In 2012 we had 9 confirmed cases, all <28 days of age. We are aware that there were several infant cases which were not reported. Please remind your colleagues of the new case definition and remember to include in your notification email to the APSU any cases up to 12 months of age.

Thank you for reporting cases to the APSU! Please report any outstanding cases for 2012 for the following studies:

Subdural Haematoma and Effusion in Children <2 years

The SDH study concluded on 31 December 2012. Please forward completed questionnaires for cases you reported last year. If you know of a case in 2012 but haven't reported it yet, please do so as soon as possible. The study has had a total of 178 case notifications since surveillance began in July 2010.

Severe Neonatal Hyperbilirubinaemia

The SNH study will be concluding on 31 March 2013. Please return any outstanding questionnaires and notify any outstanding cases that are yet to be notified. 168 cases have been notified since April 2010.

Juvenile onset Recurrent Respiratory Papillomatosis.—JoRRP

We have had very few reports of JoRRP. Although it is a very rare condition there may be some cases that are yet to be reported. Please report these as soon as possible.

Rare Disease Day 2013

The APSU held a forum for young people living with rare diseases on 23 February at Sydney University. The 15 young people and 15 parents discussed transition to adult health services and other issues they face. Participants called for better coordination of services, better preparation for transition and assistance through the transition process by transition coordinators or coaches. To read more please go to <http://www.apsu.org.au/home/news/>



The forum was a resounding success and was proudly sponsored by Rare Voices Australia, Agency for Clinical Innovation, Transition Care Network, The SMILE Foundation, and The

University of Sydney. The APSU would like to once again thank all of these organisations for their support.

Do you have an idea for an APSU Study ?

We have had a number of expressions of interests regarding potential APSU studies including:

- ◆ Children's Interstitial Lung Disease—likely to begin July 2013
- ◆ Foetal Alcohol Spectrum Disorder—likely to begin July 2013
- ◆ Chronic Fatigue Syndrome
- ◆ Eosinophilia oesophagitis

If you have a study that you feel is suitable for the APSU then we want to hear from you. Please contact our office or visit our website to obtain the Expression of Interest Form.



New image and new management for INoPSU

The International Network of Paediatric Surveillance Units (INoPSU), established in 1998, currently links 12 diverse countries who share the common purpose of conducting surveillance for uncommon childhood conditions. The APSU is further strengthening its relationship to this International Network by taking on the management of INoPSU. This is an exciting time for the APSU and we look forward to further strengthening the voice for those who are affected by a rare childhood condition throughout the world. INoPSU will be celebrating its 15th year of operation in 2013. Tell us what you think of the new look logo for INoPSU.

What else for Rare Disease Day?

SMILE Foundation hosted a walk along Bondi Beach to raise awareness on rare diseases. The Steve Waugh Foundation also raised awareness through a media campaign. For more information please visit: <http://www.rarediseasedayaustralia.com.au/> <http://www.smilefoundation.com.au/> <http://www.stevewaughfoundation.com.au/>

Recent Publications

Anderson M, Elliott EJ, Zurynski YA. Australian families living with rare disease: experiences of diagnosis, health services use and needs for psychosocial support. *Orphanet journal of rare diseases*. 2013;8(1):22. Epub 2013/02/13.

Noonan S, Zurynski YA, Currie BJ, et al. A national prospective surveillance study of acute rheumatic fever in Australian children. *Pediatric Infectious Disease Journal*. 2013;32(1):e26-32. Epub 2012/08/29.3.

McGillivray, A., Evans, N. Severe neonatal jaundice: Is it a rare event in Australia? *Journal of Paediatrics Journal of Paediatrics and Child Health* 2012; 48(9):801-807.

Munns, C.F., Simm, P.J., Rodda, et al. Incidence of vitamin D deficiency rickets among Australian children: An Australian Paediatric Surveillance Unit study. *Medical Journal of Australia* 2012; 196(7):466-468.

Argent, E., Emdler, P., Monagle, et al. Australian paediatric surveillance unit study of haemoglobinopathies in Australian children. *Journal of Paediatrics and Child Health* 2012;48(4):356-360.

Watkins, R. E., Elliott, E. J., Halliday, J et al. A modified delphi study of screening for fetal alcohol spectrum disorders in Australia. *BMC Pediatrics*, 13(1)

Marshall, H. S., McIntyre, P., Richmond, P. et al. Changes in patterns of hospitalized children with varicella and of associated varicella genotypes following introduction of varicella vaccine in Australia. *Pediatric Infectious Disease Journal* (2012)

Zurynski Y, McIntyre P, Booy R, Elliott EJ, for the PAEDS Investigators Group. Paediatric Active Enhanced Disease Surveillance (PAEDS): a new surveillance system for Australia. *Journal of Paediatrics and Child Health* 2012: August (In press).

Esterman EE, Lahra MM, Zurynski YA, Booy R, Elliott EJ. Influenza infection in infants aged <6 months during the H1N1-09 pandemic: a hospital-based cohort study. *Journal of Paediatrics and Child Health* 2012: June (accepted).

Thank you for your ongoing support and we hope you enjoy this issue of Rare Kids...The Team at APSU

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