

March 2010

Surveillance Studies

Severe Neonatal Hyperbilirubinaemia

A new study on severe neonatal hyperbilirubinaemia will commence on the April 2010 card and will be led by AProf Nick Evans and Dr Angela McGillivray. Severe prolonged neonatal jaundice has been identified as cause of neurological problems including cerebral palsy. The protocol and questionnaire will be distributed via mail and e-mail at the beginning of April. These will also be uploaded to the APSU website. Please remember to add the protocol and questionnaire to your APSU Blue Folder.

Intussusception

The Investigators of the Intussusception study wish to thank everyone who reported cases. The study will end with the April report card. Please report any outstanding cases for this study as soon as possible.

Varicella surveillance studies (Congenital varicella, Neonatal varicella and severe complications of varicella)

The varicella surveillance study group wishes to thank all clinicians reporting cases for the varicella surveillance studies. To the end of December 2009, 11 reports of congenital varicella, 25 reports of neonatal varicella and 54 reports of children hospitalized with severe complications of varicella were received. The varicella surveillance studies will continue throughout 2010. A progress report is being prepared by the study investigators. For more information about the varicella surveillance study please contact GulamK@chw.edu.au.

Highlights

Rare Diseases Workshop – 27 February 2010

To mark International Rare Diseases Day, the APSU hosted a workshop on rare diseases on 27th of February 2010 at the Children's Hospital at Westmead in Sydney. The workshop aim was to raise awareness of the impacts of rare diseases and to provide information on the latest developments on the response to rare diseases in Australia. Feedback about the workshop was positive with many responding that their awareness and knowledge of the impacts of rare diseases had been heightened at the end of the workshop, and that the presentations were extremely useful.

Workshop attendees were given an opportunity to comment on the draft National Plan on Rare Diseases. Overall there was positive feedback. Many delegates commented that they would support the establishment of an umbrella organisation for rare diseases in Australia which brings together patient/carer support groups, researchers and health professionals.

For more information on this workshop, the draft National Plan and consultation form, please visit our website www.apsu.org.au. Many thanks go to the Steve Waugh Foundation, The Kid's Research Institute, and Australian Research Alliance for Children and Youth.



Front row: Noah and Neve Walker
L to R: Steve Waugh, Darren & Susanna Walker, Sarah Walker & Liz Elliott at the Rare Diseases Workshop, on 27th of February 2010

Reporting Matters

Continuing Professional Development (CPD) credits for APSU Activities

As advised last year, if you participate in APSU surveillance, you are eligible for CPD credits. See www.apsu.org.au for more information. Submit your credits through the MyCPD framework on-line <http://www.racp.edu.au/members/ce/mopsform.cfm> or complete a machine readable card: to obtain a card, email mops@racp.edu.au or phone 02 8247 6239.

Keep a record of your cases

Please remember to fill out the yellow record sheet at the front of your 'blue folder' when notifying cases. This will be a useful prompt about which child you reported when you are filling out the questionnaire on the case. Misplaced your Blue APSU Folder? Let us know and we will send you a new one.

We need timely data. Please try to report cases for the month when they are seen. Don't forget that all questionnaires and protocols can be downloaded from the APSU website at www.apsu.org.au. Please feel free to do so and complete the questionnaire as you see cases. Then fax the questionnaire to APSU: 02 9845 3082.

Email or Snail Mail?

Did you know that 81% of our contributors are reporting by email? We like this as it saves our resources and makes it easier for you to report and keep in contact. Want to change from **reply paid mail to e-mail**? Yes? Then please contact us on +61 2 9845 3005 or email us at apsu@chw.edu.au.

Recent Publications:

Jaffe A, Zurynski Y, Beville L, Elliott E. Call for a national plan for rare diseases. *Journal of Paediatrics and Child Health* 2009; 46(1-2):2-4.

*Do you have a good idea for an APSU surveillance study?
Willing to convene a group of investigators?
If so, please contact Yvonne Zurynski to discuss possibilities.*