

September 2009

Surveillance Studies

Influenza H1N1 Pandemic

Many thanks go to everyone for reporting cases of severe complications of Influenza. So far we have received over 100 notifications from all states and territories of Australia. This is a great effort by everyone and the data will supplement and enhance other surveillance systems eg. state-based public health surveillance and the PICU data collection. Reporting of the Influenza surveillance study for 2009 will cease at the end of the September card.

In addition to the surveillance conducted by APSU we have secured additional funding under the NHMRC H1N1 Influenza Initiative to collect even more detailed data from the four hospitals participating in the PAEDS trial.

Systemic Lupus Erythematosus to be led by Dr Fiona Mackie from Sydney Children's Hospital will **commence in October 2009**. We will be distributing the protocol and questionnaire with the September APSU report card and these will be available for download as well as a Public Information Sheet for families and clinicians from our website.

Highlights

Creswick Foundation Fellowship

As part of her Creswick Fellowship, Dr Yvonne Zurynski has visited patient organisations for people affected by rare diseases: [Contact-a-Family](#); [INVOLVE](#); [Rare Diseases UK](#) and [Eurordis](#), and the rare diseases information service for clinicians, [Orphanet](#). Children and families affected by rare diseases and clinicians who look after them need information about the disease/condition, parent support groups, and access to medical and social services. Paediatric Surveillance Units are well placed to improve availability of information on rare diseases that is accessible to patients, clinicians and the public. APSU will endeavour to provide patient accessible summaries for each condition studied in the future, including a summary of the condition, support groups if these exist, and any educational opportunities for parents. The British Paediatric Surveillance Unit has already begun this process. In addition, Orphanet has developed an educational program on rare diseases that is included in the medical curriculum in France to raise awareness of rare diseases among future clinicians, and to inform them of databases and search tools they may need when faced with diagnosing and managing people with rare diseases.

Recent Publications

Michael M, Elliott EJ, Craig JC, Ridley G, Hodson EM. Interventions for haemolytic uraemic syndrome and thrombotic thrombocytopenic purpura: a systematic review of randomised controlled trials. *American Journal of Kidney Diseases*. 2009; 53(2):259-72.

Peadon E, Rhys-Jones B, Bower C, Elliott E. Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatrics* 2009, 9: 35.

He S, Zurynski Y, Elliott E. Evaluation of a national resource to identify and study rare diseases: the Australian Paediatric Surveillance Unit. *Journal of Paediatrics and Child Health*. 2009 doi:10.1111/j.1440-1754.2009.01549.x.

<http://www3.interscience.wiley.com/cgi-bin/fulltext/122569793/PDFSTART>

Steve Waugh Foundation

Steve Waugh Foundation is committed to a coordinated approach to the service, identification, treatment and cure of rare diseases and illnesses primarily focussing on children (0-25years). APSU and Steve Waugh Foundation will pool resources to develop a working definition for a "very rare disease" that the Foundation can apply to their decision-making processes. We are excited to be working with Steve and his wonderful Foundation and we thank them for their generous support.



L-R: Lynette Waugh, Elizabeth Elliott, Steve Waugh & Yvonne Zurynski

Reporting Matters

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.

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.

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 clinicians to report and to keep in contact.

Still reporting by reply paid mail? Would you like to give e-mail reporting a try? Yes? Then please contact us on +61 2 9845 3005 or email us at apsu@chw.edu.au.

*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.*