



APSU Update



Christmas Greetings

On behalf of the APSU Board, Study Investigators and our research collaborators, the APSU team wish you a happy and safe holiday period.

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Surveillance Studies

Acute Rheumatic Fever

The Acute Rheumatic Fever (ARF) study group wishes to thank all clinicians reporting cases for this study. A total of 167 reports of ARF were received up to 31 October 2009, from all jurisdictions except Tasmania and the ACT. The ARF study will continue throughout 2010 supported by the National Heart Foundation of Australia and the new National Coordination Unit for Rheumatic Heart Disease at Menzies School of Health Research in Darwin. For more information about the ARF study please contact Sara.Noonan@menzies.edu.au

Severe Neonatal Hyperbilirubinaemia – Kernicterus

A new study on severe neonatal hyperbilirubinaemia – kernicterus will commence in the first quarter of 2010 and will be led by Dr Nicholas Evans.

Pandemic Influenza in children

We are most grateful to everyone for reporting cases of severe complications of influenza in hospitalised children. In addition to APSU surveillance, we ran hospital-based surveillance through the Paediatric Active Enhanced Disease Surveillance (PAEDS) system which we run jointly with the National Centre for Immunization Research and Surveillance. Data have been analysed and we're finding that even children who were previously healthy develop severe complications including pneumonia, encephalitis and rhabdomyolysis. Our data informed the recent decision to recommend the H1N1-09 vaccine for children aged under 9 years. The vaccine is now recommended for all children aged over 6 months. To read more please go to your local Department of Health website or [http://www.health.gov.au/internet/ministers/publishing.nsf/Content/4F56090A3625036FCA2576810002C236/\\$File/nr224.pdf](http://www.health.gov.au/internet/ministers/publishing.nsf/Content/4F56090A3625036FCA2576810002C236/$File/nr224.pdf)

Neuromuscular Disorders of childhood

The Neuromuscular Disorders (NMD) of childhood study will conclude with the December card. On behalf of the study team, Dr Monique Ryan would like to thank all clinicians who participated in providing information for this study. To date, 373 cases of NMD have been reported. If you have any outstanding cases to report for this study please do so as soon as possible.

*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.*

Highlights

Rare Diseases Workshop – 27 February 2010

To mark International Rare Diseases Day, the APSU will host a Workshop on Rare Diseases on 27th of February 2010 at the Children's Hospital at Westmead in Sydney. The workshop aims 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. For more information on this workshop, or if you are interested in attending please contact the APSU on 02 98453005 or APSU@chw.edu.au

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.

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.

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.

Recent Publications:

Grenier D, Lynn R, Zurynski Y et al Public health impacts of the international network of paediatric surveillance units. *Paediatrics and Child Health* 2009; 14(8):499-500.

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; 45(9):498-504.

Jaffe A, Zurynski Y, Beville L, Elliott E. Call for a national plan for rare diseases. *Journal of Paediatrics and Child Health* 2009 DOI: 10.1111/j.1440-1754.2009.01608.x
<http://www3.interscience.wiley.com.ezproxy2.library.usyd.edu.au/cgi-bin/fulltext/123189130/PDFSTART>

Lester-Smith D, Zurynski Y, Booy R, Festa M, Kesson A, Elliott E. The burden of childhood influenza in a tertiary paediatric setting. *Communicable Disease Intelligence* 2009; 33(2): 209-15.

McDonald AM, Zurynski Y, Wand HC, Giles ML, Elliott EJ, Ziegler JB, Kaldor JM. Perinatal exposure to HIV among children born in Australia, 1982-2006. *Medical Journal of Australia* 2009; 184(9): 474-475.

The APSU office will be closed from December 21 to January 4, 2010.

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