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28th February 2009

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Comments and Contributions for the next newsletter are welcome

Contact Us

If you have any comments about this newsletter or would like to contribute something to the next newsletter email:

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<http://www.inopsu.com>

Yearly review

Dr Daniel Virella – I have the pleasure and daunting task of taking over for the next 3 years the convensorship of INOPSU from Rob Rodrigues Pereira. Can I take this opportunity of thanking Rob for all his hard work in maintaining the functionality of the network these past two years. On behalf of the Portuguese unit I am very proud to have been appointed by my peers to this position. Unfortunately as mentioned by Rob in the last e-newsletter we have recently been made aware that the Malaysian unit and New Guinea unit have ceased surveillance. Though in the case of the latter Rob is trying to re-establish contact. The Trinidad and Tobago unit has also failed to materialise. However, we do have interest from a group of Italian paediatricians which we are exploring. Given all this it is probably time for the network to consolidate, making sure that the existing units remain strong and viable. Centralising the INOPSU administration within the UK will improve communication.



Over the next couple of years I aim to consider ways in which to strengthen the connections not only between units but also those who use the units. One way will be to raise the profile of INOPSU, its activities and output and to encourage closer associations between those units undertaking similar studies. Developing our web site would be one way, encouraging attendance at international conference another. With regards funding I would appreciate if all those units who can make provisions to fund our central administration to try and do so. I gather the new invoices will be sent out soon. As you know the EU Framework programme continues not to recognise the potential of INOPSU. This is more the galling when the recent EU council recommendation on European action in the field of rare diseases [SEC(2008)2712/3] specifically identifies the need to perform epidemiological research on these disorders' [which] requires multi-country approaches to increase the number of patients for each study. Further recommendations include the need for a national plan for rare disease. Perhaps here INOPSU units can influence their governments to produce such plans. We will keep an eye out for new funding calls and consider whether we should re-apply.

GLOBAL RARE DISEASE DAY – FEBRUARY 28TH

For further information [click here](#)

• **Latest INoPSU publications**

APSU: Click here - [APSU report 2005-2006](#)

Gleeson H K, Wiley V, Wilcken B, Elliott E, Cowell C, Thonsett M, Byrne G & Ambler G. Two-year pilot study of newborn **screening for congenital adrenal hyperlasia** in New South Wales compared with nationwide case surveillance in Australia. *Journal of Paediatrics and Child Health* 44 (10) 2008; 554-559.

Giles ML, McDonald AM, Elliott EJ, Ziegler JB, Hellard ME, Lewin SR, Kaldor J. Variable uptake of recommended interventions to reduce mother-to-child transmission of **HIV** in Australia. *Medical Journal of Australia*, 1982-2005. 189(3):151-4, 2008 Aug 4.

Zurynski Y, Frith K, Leonard H, Elliott EJ. Rare childhood diseases: how should we respond? *Arch. Dis. Child* 2008; 93(12):1071-4 *Online First*, 06 August 2008. doi:10.1136/adc.2007.134940

BPSU: Salotti JA, Nanduri V, Pearce MS, Parker L, Lynn RM, Windebank KP. Incidence and clinical features of **langerhans cell histiocytosis** in the UK and Ireland *Arch. Dis. Child.*, Dec 2008; doi:10.1136/adc.2008.144527

Shield JPH, Lynn R, Wan KC, Haines LH, Barrett TG. Management and one year outcome for UK children with **type 2 diabetes**. *Arch. Dis. Child.*, Oct 2008; doi:10.1136/adc.2008.143313

- **New INoPSU studies**

CPSP: September 2008 for MRSA in hospitalised children. January 2009 Serious adverse events with paediatric complementary and alternative medicine (CAM) commence.

Melamine contamination of dairy products in China – public health impact

- The New Zealand and Canadian Paediatric Surveillance systems have undertaken a retrospective one year surveillance renal stones and/or acute renal failure in infants under the age of one to check that there had been no cases of melamine-associated stones. Data is currently being written up and we will let you have details as soon as possible. In the meantime you can contact the researchers at Danielle Grenier - danielleg@cps.ca and Nigel Dickson- nigel.dickson@otago.ac.nz

Rare disease News

- **Conferences & Meetings**

British Paediatric Surveillance Unit conference will be held on 3rd March 2009 at the Royal Institute of British Architecture. Presentations on the following themes will be given; infectious disease in children; informing policy and practice; developing partnerships. For more information visit http://bpsu.inopsu.com/home/2009_conference.htm

- **Australian Paediatric Surveillance Unit** is holding a meeting on February 9th to draft a national plan for rare diseases. The meeting will involve the Royal Australasian College of Physicians Division of Paediatrics and Child Health, consumer groups, clinicians and researchers interested in rare diseases, children's charities, and the NSW Commissioner for Children

- **Public/Patient Involvement**

Creswick Foundation Fellowship awarded to Yvonne Zurynski to enable overseas travel to study support services offered to families affected by rare diseases