

6th INoPSU Conference – 7TH – 8TH October

Call for abstracts

The 2010 INOPSU meeting will be held in Dublin, Ireland, on Thursday 7th and Friday 8th October. The meeting will be hosted by the Faculty of Paediatrics of the Royal College of Physicians of Ireland (RCPI).

A scientific meeting, which will be open to participants outside of INOPSU, will be held on Thursday 7th October. The INOPSU business meeting will be held on the morning of Friday 8th October. Further details of the meeting, along with a more extensive accommodation list and travel details, will be available in the coming weeks.

In the meantime, I would like to invite you, or your colleagues, to submit abstracts for the scientific meeting. Subject areas that would be particularly relevant to the meeting include:

- Surveillance studies that involve international collaboration
- Studies on subject areas that have international relevance (e.g. pandemic influenza, early onset eating disorders, HIV etc.)
- Studies that highlight challenges, or innovative solutions, to paediatric surveillance

Please forward abstracts by e-mail to gary.brady@cuh.ie by Friday 2nd April.

In addition, please let me know if you have any suggestions or requests for topic areas you would like to see included in review/keynote presentations.

Details of the venue, including a list of nearby hotels, can be found at www.rcpi.ie

Looking forward to seeing you in Dublin.

Robert Cunney - Irish Paediatric Surveillance Unit (IPSU) Coordinator

INoPSU signs up to International Rare Disease Day

The 28th of February has been designated International Rare Disease Day. This day is an annual awareness raising event co-ordinated by **EURORDIS** at an international level and National Alliances of Patient Organisations at a national level. This year Rare Disease Day will serve to highlight the commitment of the European Union to enhance research in the field of rare diseases, as stated in the Council Recommendation for Action in the field of Rare Diseases, adopted by all EU Health Ministers in June 2009.

In the UK, Rare Disease Day is being coordinated by the Genetic Interest Group, the UK alliance for all people affected by genetic conditions and Rare Disease UK, a multi-stakeholder group brought together to develop strategic planning for rare diseases in the UK. For further details visit

<http://www.rarediseaseday.org/2010/country/uk/united%20kingdom>.

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

We would encourage all units to use the opportunity to publicise their work and activities.

In This Issue

INOPSU 6th Conference –
7-8th October 2010

Rare Disease Day

INoPSU signs up

Study database developed

INoPSU database to link
researchers now available.

New INoPSU studies

Recent Publications

**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:

bpsu@rcpch.ac.uk

<http://www.inopsu.com>

INoPSU study database developed

INoPSU members have supplied a list of all their individual studies, contacts and publications. From this we can see that INoPSU has facilitated surveillance of over 200 conditions. 49 conditions have been studied in more than one country. It is hoped that this listing can be used to link investigators around the world allowing for protocol sharing and data comparison.

New studies: CPSP - adrenal suppression, persistent albuminuria in children with T2DM, and Respiratory syncytial virus (RSV) infections in transplant patients. **APSU:** severe neonatal hyperbilirubinaemia and in October 2009, APSU commenced a study on Systemic Lupus Erythematosis (SLE) in order to estimate the incidence, geographical distribution and ethnic background of children aged ≤ 15 years diagnosed with SLE in Australia. This study will also describe the mode and severity of clinical presentation as well as 1 year outcome. Further information: www.apsu.org.au

BPSU: congenital syphilis; Gonorrhoea, Syphilis, Chlamydia, and Trichomonas infections in children aged 1 year up to thirteen years presenting to secondary care

Recent publications

INoPSU:

1. 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.

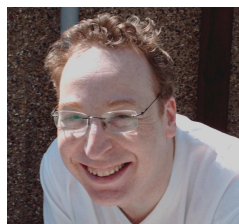
APSU:

1. 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.
2. 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>
3. 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.
4. 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.
5. Madden S, Morris A, Zurynski Y et al. Burden of eating disorders in 5-13 year old children in Australia. **MJA 2009. 190; 410-414**
6. McDonald A, Zurynski Y et al. Perinatal exposure to HIV among children born in Australia, 1982-2006. **MJA 2009. 190; 416-420**

CPSP

1. Adverse events associated with paediatric use of complementary and alternative medicine: Results of a Canadian Paediatric Surveillance Program survey. S Vohra, J Brulotte, C Le, T Charrois, H Laeque, *Paediatr Child Health*, vol 14, no6, July/august 2009, 385-7.
2. Incidence of acquired demyelination of the CNS in Canadian children. B. Banwell et al. *Neurology* 2009;72;232-239.

And Finally



Congratulations to Richard Lynn, Scientific Coordinator of the BPSU, who celebrates 20 years in the post. Many of the achievements of INoPSU could not have been made possible without his input – thanks Richard from us all