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<http://www.inopsu.com>

6th INOPSU Conference a great success



The 6th meeting of the **International Network of Paediatric Surveillance Units** (INOPSU) was held in Dublin on the 7th and 8th of October 2010. The meeting coincided with the Faculty of Paediatrics of the Royal College of Physicians of Ireland annual scientific conference. Fifteen representatives from seven & different INOPSU units were present including: UK, Ireland, Canada, Australia, Netherlands, Switzerland and Portugal, with only representatives from New

Zealand, Wales, Greece, Germany and Latvia unable to attend.

The meeting provided an excellent opportunity for representatives from each of the national units to meet and exchange views on rare disease surveillance and discuss issues that currently pose challenges to the units. Funding and the increasingly cumbersome processes for ethical approval of surveillance studies were a particular focus.

The meeting comprised of two days, a one day scientific meeting, followed by the INOPSU business meeting. The scientific program included the following presentations:

- Improving the medical care in rare diseases,: Key note address, Dr Ségolène Ayme from ORPHANET
- HIV/AIDS and Lead poisoning in children (Ire)
- Pandemic influenza H1N1 in children (Aus)
- Surveillance and beyond, Challenges and innovative solutions in national surveillance and Public health impacts of INOPSU on disease surveillance (Can)
- Sexually-transmitted infections, TB, Toxic shock syndrome, Early onset eating disorders and fast-track surveillance for public health emergencies – Is it possible? (UK)

The presentations can be downloaded from

<http://www.inopsu.com/publications/index.html>.

Dr Ana Rath of Orphanet (www.orphanet.org) – the EU funded web portal for Rare disease – presented the work of the network and discussions on how INOPSU could collaborative from the paediatric dimension was discussed.

The following day a business meeting was held to discuss recent developments, as well as the future direction of INOPSU.

It was reported that a database which lists all 200 individual conditions that INOPSU units have surveyed, along with the researchers, their contact details and resulting publications, has now been established. This will be a valuable resource to enable collaboration across units, and it is hoped that in the future, papers will be produced using data obtained across the participating countries. Plan to make this database more accessible via the INOPSU website were discussed.

A new work programme was also agreed, the main aim being to increase the profile of INOPSU's achievements and outcomes. Initiatives to do this include collaborating with European organisations such as Orphanet and the European Academy of Paediatrics. INOPSU also intends to increase its involvement in Rare Disease Day 2011 in a number of countries.

Danielle Grenier from Canada and Yvonne Zurynski from Australia were elected as the

new INoPSU co-chairs for the next 3 years. They will be replacing Daniel Virella from the Portuguese unit, who was thanked for his work, along with Helen Friend and Richard Lynn who provide coordination and administration support to INoPSU.

All those who attended the event expressed their thanks to Robert Cunney and Sandra Morgan of the Irish unit for organising a very successful conference.

INoPSU representation at International Conferences

Excellence in Paediatrics: Saturday 4th December 2009, London. The BPSU has been invited to run a workshop at this international conference. The session will be chaired by Professor Alan Emond who will speak on the work of the BPSU and INOFSU; he will be supported by talks from Dr Chris Verity; Professor Carol Dezateux and Dr Deidre Kelly. The conference has a very wide international flavour and will give INOFSU an opportunity to reach out to a wide range of clinicians and researchers.

BPSU celebrates 25th Anniversary with Symposium: June 2012 sees the completion of 25 years of surveillance. During this period it has facilitated surveillance of over 70 rare conditions. The data gathered has led to over 200 peer review papers. The information has led to changes in national and international rare disease planning and policy development. As early as 1992 the unit was working with fledgling units in Germany and Netherlands to undertake multi-national surveillance of conditions such as vitamin K deficiency bleeding and Haemophilus b vaccine efficacy. The BPSU was an INOFSU founder member.

To celebrate its achievements a symposium is to be held on Tuesday 5th April 2011 as part of the Royal Colleges scientific meeting. Guest speakers will include Dr Chris Verity; past BPSU chair; Dr Jugnoo Rahi, scientific coordinator of the ophthalmic surveillance unit, Professor Carol Dezateux and Professor Elizabeth Elliott, Director of the Australian unit, will be the Key note speaker.

Further details will be available in the new year but if you are interested in attending please contact Helen.friend@rcpch.ac.uk

Recent publications

INoPSU 2009 annual report: This report summarises the work of the units over 2009. It can be downloaded from the INoPSU website. [Click Here](#)

Several units have recently published their latest annual reports and these can be downloaded at the following. For the first time the Swiss annual report has been published in English and is also available on-line

APSU: [Click here](#) **BPSU:** [Click here](#); **CPSP:** [Click here](#); **SPSU:** [Click Here](#)

News in General

Rare Disease Day 2011: INoPSU aim to take a more active role in International Rare Disease day to be held on 28th February 2011. The BPSU will be attending a parliamentary reception to support the work of developing a UK plan for rare disease. The APSU will be holding a variety of activities including the Second Rare Diseases Workshop for families and clinicians.

Orphanet: Following initial contact in Dublin INOFSU hope to have closer contacts with Orphanet. We hope to encourage the use of data generated by INoPSU units on rare diseases on their extensive website www.orphanet.org and to encourage paediatricians to use this excellent source of information about rare diseases.