

International Developments



The International Network of Paediatric Surveillance Units (INoPSU), established in 1998, continues to enhance collaboration between national paediatric surveillance units. INoPSU provides a unique opportunity for simultaneous cross-sectional studies of rare diseases in populations with diverse geographic and ethnic characteristics.

Currently, there are 12 national paediatric surveillance units worldwide that are full members of INoPSU: Australia, Britain, Canada, Cyprus/Greece, Germany, Ireland, Latvia, Netherlands, New Zealand, Portugal, Switzerland and Wales. The British Ophthalmological Surveillance Unit is an associate member.

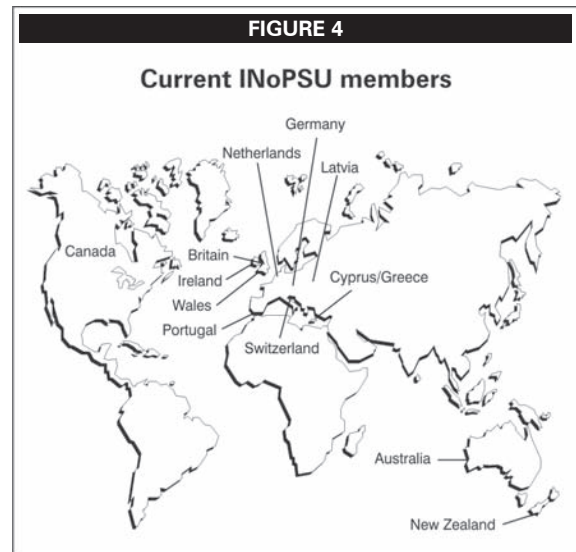
2010 highlights

The 6th INoPSU meeting was held in Dublin, Ireland on October 7–8, 2010, and 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 (www.inopsu.com).

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 ethical approval of surveillance studies were a particular focus.

The two-day meeting comprised a one-day scientific meeting, followed by the INoPSU business meeting. The scientific program included the following presentations:

- Key note address by Dr. Ségolène Ayme from Orphanet: Improving the medical care in rare diseases



- HIV/AIDS and lead poisoning in children (Ireland)
- Pandemic influenza H1N1 in children (Australia)
- Surveillance and beyond: The Canadian experience; Challenges and responses: The Canadian Paediatric Surveillance Program; and Public health impacts of INoPSU (Canada)
- Sexually-transmitted infections, tuberculosis, toxic shock syndrome, early-onset eating disorders, lead poisoning, and fast-track surveillance for public health emergencies (United Kingdom)

Yvonne Zurynski from Australia and Danielle Grenier from Canada were elected as new INoPSU co-chairs for the next three years.

Preparations are well underway for the 7th INoPSU meeting to be held in Montreux, Switzerland, September 1–2, 2011. The meeting will be hosted by the Swiss Paediatric Society.

Rare Disease Day – February 28 www.rarediseaseday.org

Rare Disease Day is marked across the globe as an annual, awareness-raising event coordinated by EURORDIS at the international level and by the International Alliance of Patients' Organizations at the regional level.

In the United Kingdom, Rare Disease Day is being coordinated by the Genetic Alliance UK, an interest group for all people affected by genetic conditions, and Rare Disease UK, a group brought together to develop strategic planning for rare diseases.

INoPSU units were involved in several activities. The Australian Paediatric Surveillance Unit hosted a workshop on rare diseases at the Children's Hospital at Westmead in Sydney, on February 27, 2010.

Publications from INoPSU members

Australian Paediatric Surveillance Unit (APSU)

He S, Zurynski Y, Elliott E. What do paediatricians think of the Australian Paediatric Surveillance Unit? *J Paediatr Child Health* 2010; 46: 412-8

Jaffe A, Zurynski Y, Beville L, Elliott E. Call for a national plan for rare diseases. *J Paediatr Child Health* 2010; 46: 2-4.

British Paediatric Surveillance Unit (BPSU)

Verity C, Winstone AM, Stellitano L, Krishnakumar D, Will R, McFarland R. The clinical presentation of mitochondrial diseases

in children with progressive intellectual and neurological deterioration: a national, prospective, population-based study. *Dev Med Child Neurol* 2010; 52(5): 434-40

German Paediatric Surveillance Unit (ESPED)

Göbel U, Heinrich B, Krauth K, Steingrüber H.-J., von Kries R. Evaluation der Prozess- und Ergebnissqualität der Erhebungseinheit für seltene pädiatrische Erkrankungen in Deutschland (ESPED) – Process and outcome quality of the German Paediatric Surveillance Unit. *Klin Padiatr* 2010; 222: 92-7

Netherlands Paediatric Surveillance Unit (NSCK)

van Hoof JJ, van der Lely N, Pereira RR, van Dalen WE. Adolescent alcohol intoxication in the Dutch hospital Departments of Pediatrics. *J Stud Alcohol Drugs* 2010; 71: 366-72

Swiss Paediatric Surveillance Unit (SPSU)

Fanconi M, Lips U. Shaken baby syndrome in Switzerland: results of a prospective follow-up study, 2002-2007. *Eur J Pediatr* 2010; 169: 1023-8

Further publications can be found at www.inopsu.com.



INoPSU conference, Dublin, Ireland, October 2010