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<http://www.inopsu.com>

4th Rare disease day a success

Rare disease day celebrated on 28th February.

The 4th Rare Disease Day took place on the 28th February. Rare Disease Day began as a European initiative and is now marked across the globe as an annual, awareness-raising event coordinated by EURORDIS at the international level and by the National Alliances of Patient Organisations at the national level. Hundreds of patient organisations from more than 40 countries worldwide organised awareness-raising activities and converging around this years theme of "Rare but Equal".



Rare Disease day aims to draw attention to:

- Gaps in health that exist for rare disease patients between and within countries in the EU.
- Gaps in health that exist for rare disease patients compared to other sectors of society.

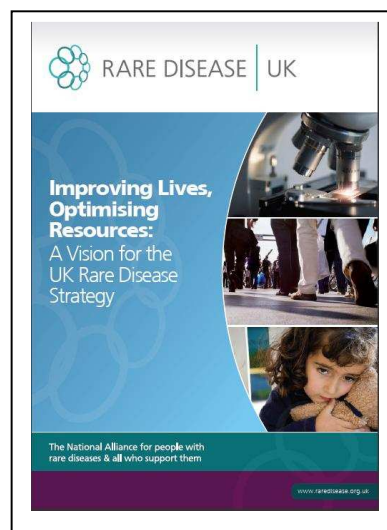
The campaign will serve to advocate for:

- Equal access for rare disease patients to health care and social services.
- Equal access to basic social rights: health, education, employment, housing.
- Equal access to orphan drugs and treatments

INoPSU units were involved in several activities most notably the Australian unit.

Activities undertaken included running a brief survey via their website www.apsu.org.au to enable the community to express their support for a national plan for rare diseases in Australia. A national conference "Awakening Australia to Rare Diseases" is to be held in April 2011 in Fremantle Western Australia

www.rarediseases.org.au. The APSU has also partnered with the Steve Waugh Foundation, The Smile Foundation, Association of Genetic Supports Australasia and the Sydney Children's Hospitals Network (Randwick and Westmead) to plan a research study on the impacts of rare diseases on families, on health professionals and on health services.

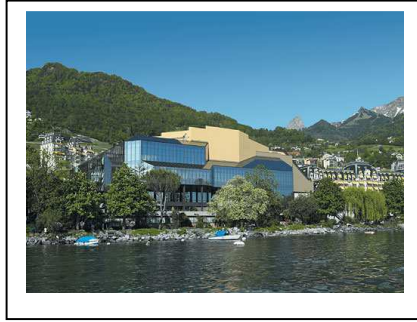


In the UK the BPSU attended a function hosted by Rare Disease UK (RDUK) in the House of Commons. To coincide with the event RDUK released a new report outlining recommendations for a strategy for rare diseases – '**Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy**'. The report is a product of a year and a half of work in collaboration with members and the broad rare disease community. The BPSU contributed, through the involvement of Richard Lynn, scientific coordinator, in addition to contributions from BPSU study investigators. This report was presented to Earl Howe, who is part of the Department of Health Ministerial team at a reception at the House of Commons.

The BPSU is now pleased to announce that it has linked with RDUK and we hope to work closely with them to promote each others activities.

7th INoPSU Symposium to be held in Switzerland

Call for abstracts



The 7th INOPSU meeting is to be held in Montreux on Friday 2nd September at the Centre de congrès et d'exposition Montreux – inset. The meeting will be held as a symposium as part of the Swiss Paediatric Society scientific meeting.

Those who wish submit an abstract to either the Swiss Paediatric Society and or INOPSU symposium according to the conference organizers, must submit abstracts to abstracts@bbscongress.ch. An SPSU-Review-Team will then select abstracts and decide

which presentations are to be given at the INoPSU symposium and which will be presented at the national paediatrics conference. For further advice get in touch with [Mirjam Mäusezahl-Feuz](#). Abstracts are required by April 30th

News in General

Collaborative research: The UK, Canadian and Australian investigators of the study on **Early onset eating disorders** are now sharing data in order to produce a comparative paper for publication. The long awaited paper on **haemolytic uraemic syndrome** is nearing completion and we hope to submit this by the Autumn. This will be timely given that the UK investigators are looking to follow up the original cohort and repeat surveillance. There is interest from the investigators in UK, Canada, Switzerland and the Netherlands who have undertaken surveillance of **severe hyperbilirubinemia** to prepare a collaborative paper. Richard Lynn is coordinating this action; if you wish to take part please do let us know.

Anyone interested in undertaking simultaneous surveillance of **Dopa-responsive dystonia**, given the rarity and the dramatic and sustained opportunity for improvement with simple oral L-Dopa medication. The Canadian unit have just approved an application. If so contact the CPSP at www.cps.ca/cpsp.

Orphanet: Orphanet, the pan-European information portal for rare diseases and orphan drugs is pleased to announce that its site is now available in Portuguese, Portuguese rare disease professionals and patient organisations are invited to register or update their activities. [CLICK HERE](#).

The UK branch of Orphanet has also launched a UK specific site - <http://www.orphanet.co.uk/> . Following discussions with the BPSU a specific paediatric section has been included on the site. Suggestions on what should be included in this paediatric section are welcomed.

Expanding the network to other countries: The INOPSU office has been contacted by researchers in Belgium informing us of the development of a Belgium Paediatric Surveillance Unit. Unbeknown to INOPSU this Unit has been active for some time. They have approached us to join our activities and we would wish to accept them into our family at our next business meeting.

The CPSP in collaboration with Dr Raul Mercer, Argentina, will be participating in a workshop entitled "Paediatric Surveillance - A core medical and public health function" at the Latin American Paediatric Association (ALAPE) Congress of Pediatrics April 6-10, in Panama. This is an invitational workshop for representatives from National Paediatric Societies and Public Health Departments. The goal is to introduce active surveillance and invite participating countries to become INoPSU Associate Members.

Recent publications

INOPSU: Dr Rob Pereira from the Dutch unit will be presenting an INOPSU poster at the European Society for Infectious Disease meeting in The Hague in June.

Britain: Surveillance of congenital cytomegalovirus in the UK and Ireland. Claire L Townsend, Catherine S Peckham, Pat A Tookey ADC-FNN 2011 has recently been published on-line and can be viewed at

<http://fn.bmj.com/content/early/2011/02/01/adc.2010.199901.full.pdf>

Childhood eating disorders: British national surveillance study. Nicholls D. E., Lynn R. and Viner R. M. *British Journal of Psychiatry* Apr 1, 2011; 198 (4).

Wales: 1. 2011 Gupta K, Warner J. Inappropriate and inconsistent modalities of treatment of Vitamin D deficiency in children. *BMJ* 2011.

http://www.bmj.com/content/340/bmj.b5664/reply#bmj_el_233824?sid=8c413d71-ec6d-40c8-89e1-22dfcbf54d59

Canada: The CPSP: Celebrating 15 years of successful paediatric surveillance. Anne-Marie Ugnat, Danielle Grenier, Melanie Laffin Thibodeau, Marie Adèle Davis. *Paediatr Child Health*, April 2011, 16 (4)

Australia: Congenital and neonatal varicella: impact of the national varicella vaccination program in Australia. Khandaker G, Marshall H, Peadon E, Zurynski Y, Burgner D, Buttery J, Nissen M, Elliott E, Burgess M, Booy R. *Archives of Disease in Childhood* 2011; (on-line first DOI: 10.1136/adc.2010.206037).

Adverse events associated with the use of complementary and alternative medicine in children. Lim A, Cranswick N, South M. *Archives of Diseases in Childhood* 2010, (on-line first DOI: 10.1136/adc.2010.183152).

Persistence of acute rheumatic fever in a tertiary children's hospital. Smith M, Lester-Smith D, Zurynski Y, Elliott E, Noonan S, Carapetis J. *Journal of Paediatrics and Child Health* 2010(on-line first doi:10.1111/j.1440-1754.2010.01935.x)