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Contact Us

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INOPSU Launch E-newsletter

Welcome to what we hope will be a regular E-newsletter highlighting the work of INOPSU and identifying other activities relating to paediatric rare disease.

For those not familiar with INOPSU, we were set up in 1998 as a worldwide network to increase the communication between researchers undertaking surveillance of rare paediatric diseases. INOPSU currently consists of 12 national surveillance units across 3 continents from Canada to Australia. It involves 10,000 clinicians covering a child population of 50 million children. Between the existing units the epidemiology of over 150 rare paediatric conditions have been investigated. In 2007 nearly 100 conditions were studied.

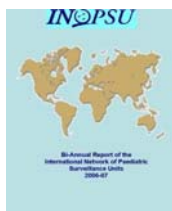
Further details on INOPSU is available from its website www.inopsu.com

Rob Pereira

INOPSU Convenor



Latest INOPSU publications



[INOPSU annual report](#) – 2006-7 now out

Beyond Counting Numbers – Public Health Impact of Studies Conducted through National Paediatric Surveillance Units. Grenier D et al. *Arch Dis Child* Jun 2007; 92: 527 - 533

▪ New INOPSU studies

UK – [Intussusception](#). First UK paediatric surveillance to involve paediatric surgeons as well as paediatricians.

▪ Rare disease News

Public Consultation regarding a European Action in the Field of Rare Diseases. Have your say in this EU consultation process. [For more information](#)

First European "Rare Disease Day" 29th February 2008. Visit the [website](#) for further details and activities in your country.

Increasing prevalence of rare diseases amongst Bradford England's Pakistani population – [OrphaNews Europe](#) interview Dr Peter Corry.

▪ Conferences

INOPSU - To be held in Munich September 11-14th 2008. For further details contact bpsu@rcpch.ac.uk

ICORD 2008: 4th International Conference on Rare Diseases and Orphan Drugs 20-22 May 2008, Washington D.C., USA. For more information: www.icord.se