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**Rare Disease Day Activities**

**Young people living with rare disease call for better health services and peer support.**

The APSU held a forum on Saturday the 23<sup>rd</sup> of February at the University of Sydney, which identified gaps and needs for young people living with complex, chronic rare diseases and medical conditions. Young people aged 15 to 23 years, and parents attended. Many described the transition from paediatric services to adult health services as a “trial”.

They described difficulties such as finding the right specialists and GPs who are willing to take on their case; lack of coordination among services and lack of peer support while transitioning. Young people and their parents called for enhanced transition services with adequate preparation for transition; better linking between paediatric and adult health services and a “One Stop Shop” where they could access a case manager or “transition coach”, who could help them navigate the transition process, including dealing with agencies such as Medicare and private health insurance providers.

At the end of the Forum, young people resolved to develop an on-line support community for young people living with rare diseases. A report from the forum is in preparation and will be available at: [www.apsu.org.au](http://www.apsu.org.au) and an editorial was published in the Medical Journal of Australia

**8<sup>th</sup> INOPSU Symposium to be held in Melbourne 2013**



Melbourne, Australia is hosting the 27<sup>th</sup> International Congress of Paediatrics (ICP) between 24<sup>th</sup> – 29<sup>th</sup> August 2013. The theme is Bridging the gap in child and adolescent health. Leading experts will explore different opinions, treatment methodologies, and practices of paediatric and adolescent care.

INOPSU will hold its biennial Symposium and a business meeting and dinner on the 24<sup>th</sup> of August 2013. The program has been uploaded to the congress website. Please contact Yvonne Zurynski [yvonne.zurynski@health.nsw.gov.au](mailto:yvonne.zurynski@health.nsw.gov.au) for further information.

The ICP programme is very exciting and we invite you to attend the INOPSU Symposium as well as the rest of the ICP Programme. A session on rare diseases research will be held on the 25<sup>th</sup> of August. Further details are available at the ICP website. <http://www2.kenes.com/IPA/Pages/home.aspx>

### New Studies started in 2012/2013

- APSU:**
- Eosinophilic Oesophagitis
  - Severe complications of Influenza (reinstated)
- WPSU:**
- Epidemiology and management of acute pancreatitis in children in Wales
- CPSP:**
- Unexpected sudden infant death and severe apparent life-threatening events in the early post-natal period.
  - Severe Alcohol intoxication in adolescents
- SPSU:**
- Pertussis
  - Kawasaki Disease
- BPSU:**
- Acute pancreatitis
  - Kawasaki Disease

### Studies in the pipe line

- WPSU:**
- Presentation, Management and complications of preseptal and orbital cellulitis
  - Brachial plexus injury
  - Childhood meningitis
  - Non-Accidental head injury
- CPSP:**
- Childhood tuberculosis
  - Hypoglycemia in low-risk term Infants
  - Sudden unexpected death in epileptic patients
  - Biphasic and delayed anaphylaxis in children
- SPSU:**
- Tuberculosis in children
- BPSU:**
- Acute Rheumatic fever
  - Acute Hepatitis
  - Blood exchange transfusion
  - Group B Strep

### Educational meetings and conferences

#### 1. CPS Annual Conference

<http://www.annualconference.cps.ca/>

CPSP concurrent session will be:

"Understanding Conversion Disorder: Does the Mind Rule the Body or Does the Body Rule the Mind?" Catherine Krasnik and Christina Grant, principal investigators.

2. International Meeting on Indigenous Child Health, April 19-1,2013 Portland, Oregon."Surveillance as a tool to serve Aboriginal health needs". D Grenier et al. (poster presentation)

3. Early –onset eating disorders: multi-national comparisons, European Paediatric Association Congress, Glasgow, 5-8th June, R.Lynn et al (oral presentation)

4. INOPSU talk at EPA meeting in Glasgow, R Lynn

5. 15 years of the International Network of Paediatric Surveillance Units: The usefulness of structured systems for surveillance of paediatric uncommon conditions. Child 2025, Dublin 30-31 May 2013, Daniel Virella (poster presentation)

## Recent INoPSU Publications

### CPSP:

Campbell C, Levin S, Siu VM, Venance S, Jacob P. Congenital Myotonic Dystrophy: Canadian Population-Based Surveillance Study. on line: <http://www.ncbi.nlm.nih.gov/pubmed/23415617> . *J Pediatr* 2013 Feb 14. pii: S0022-3476(12)01559-4. doi: 10.1016/j.jpeds.2012.12.070. [Epub ahead of print]

Can surveillance provide epidemiological data on Aboriginal health? *Paediatr Child Health* 2012;17(8):441-2. <http://www.cpsp.cps.ca/publications/commentaries-in-paediatrics-child-health>

### SPSU:

Laubscher B, Bänziger O, Schubiger G. Prevention of vitamin K deficiency bleeding with three oral mixed micellar phyloquinone doses : results of a 6-year (2005-2011) surveillance in Switzerland. *Eur J Pediatr* 2013;172(3):357-360. <http://www.cpsp.cps.ca/uploads/publications/Highlights-obesity-hypoventilation-syndrome.pdf>

### BPSU:

Busfield, Alison; Samuel, Rebecca; McNinch, Andrew; *et al.* Vitamin K deficiency bleeding after NICE guidance and withdrawal of Konakion Neonatal: British Paediatric Surveillance Unit study, 2006-2008 . *Arch Dis Child* 2013; 98: 41-47

SJ Oddie, V Craven, K Deakin, J Westman, A Scally. Severe neonatal hypernatraemia: a population based study. *Arch Dis Child Fetal Neonatal Ed* 2013;0:F1-F4.

C Ani, R Reading, R Lynn, S Forlee, E Garralda. Incidence and 12-month outcome of non-transient childhood conversion disorder in the UK and Ireland. *BJP* published online April 25, 2013 Access the most recent version at DOI: 10.1192/bjp.bp.112.116707

### APSU:

Zurynski YA, McIntyre P, Booy R, Elliott E.J. On behalf of PAEDS Investigators Group. Paediatric Active Enhanced Disease Surveillance: A new surveillance system for Australia. DOI: 10.1111/jpc.12282

Esterman EE, Lahra MM, Zurynski YA, Booy R, Elliott EJ. Influenza infection in infants aged <6 months during the H1N1-09 pandemic: A hospital-based case series. DOI:10.1111/jpc.12266

Anderson, Matilda; Elliott, Elizabeth J.; Zurynski, Yvonne A. Australian families living with rare disease: experiences of diagnosis, health services use and needs for psychosocial support. *ORPHANET JOURNAL OF RARE DISEASES* 2013; 8:22 DOI: 10.1186/1750-1172-8-22

Noonan, Sara; Zurynski, Yvonne A.; Currie, Bart J.; *et al.* A National Prospective Surveillance Study of Acute Rheumatic Fever in Australian Children. *PEDIATRIC INFECTIOUS DISEASE JOURNAL* 2013; 32(1):E26-E32

Khandaker, G.; Rashid, H.; Zurynski, Y.; *et al.* Nosocomial vs community-acquired pandemic influenza A (H1N1) 2009: a nested case-control study. *JOURNAL OF HOSPITAL INFECTION* 2012; 82(2 ): 94-100

Zurynski YA, Elliott E.J. Challenges of transition to adult health services for patients with rare diseases. *Medical Journal of Australia* 2013; 198(11):575-576



**INoPSU website: A new website is currently under development.**

**We hope to launch the new site at the ICP in Melbourne. Meanwhile if you need any information about INoPSU please go to [www.inopsu.com/](http://www.inopsu.com/) or contact the APSU: [apsu@chw.edu.au](mailto:apsu@chw.edu.au) or the BPSU: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk) or any of the individual units listed below**



- ◆ Australian Paediatric Surveillance Unit (APSU)
- ◆ British Paediatric Surveillance Unit (BPSU)
- ◆ Belgium Paediatric Surveillance Unit (BePSU)
- ◆ Canadian Paediatric Surveillance Programme (CPSP)
- ◆ German Paediatric Surveillance Unit (ESPED)
- ◆ Greece and Cyprus Paediatric Surveillance Unit (GCPSU)
- ◆ Netherlands Paediatric Surveillance Unit (NSCK)
- ◆ New Zealand Paediatric Surveillance Programme (NZPSU)
- ◆ Swiss Paediatric Surveillance Unit (SPSU)
- ◆ Welsh Paediatric Surveillance Unit (WPSU)
- ◆ Portuguese Paediatric Surveillance Unit (PPSU)
- ◆ Irish Paediatric Surveillance Unit (IPSU)
- ◆ Greece and Cyprus Paediatric Surveillance Unit (CPSU)