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Public involvement -

Creswick Foundation Fellowship
awarded to Yvonne

**Comments and Contributions
for the next newsletter are
welcome**

Contact Us

If you have any comments
about this newsletter or
would like to contribute
something to the next
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Swine flu outbreak in Mexico leads to world pandemic

Dr Daniel Virella – Since our last e-newsletter the world has succumbed to the flu pandemic that has been forecasted for several years. The first since the 1957 outbreak, H1N1 flu virus were initially reported in Mexico City in March. The virus spread quickly to the USA; Scotland, Spain and most noticeably the rest of the UK, even though this is their summer period. Reports have occurred now across the globe but thankfully the initially reports that appeared to show a high virulence appears now not to be the case. In most cases this is a mild illness for which recovery is swift. However, for vulnerable groups concern remains. In the UK there is strong evidence that children and young adults are disproportionately being affected. There have also been reports of 2 deaths in pregnant women in the UK. INoPSU is in an excellent position to support research into the emerging epidemiology of this virus. As I write surveillance of severe complications in children of all flu is being carried out in Australia; a similar study is being planned in the UK. A vaccine is currently under trial and is expected to be available near the end of the year. In the meantime you should consider how your surveillance unit can support the national authorities in identifying likely adverse reactions. BPSU in the UK is considering undertaking surveillance of Guillain Barre syndrome and the APSU is amending its protocols to cover this condition.



Other news: I am pleased to say that the EU has recently adopted The EU Council's Recommendation on a European action in the field of rare diseases. For further details on this please [click here](#).

And welcome back the Malaysian Paediatric Surveillance Unit. The MPSU has been reactivated following Dr Rowani's return from Australia. It remain as a unit under the umbrella of the Malaysian Paediatric Association, <http://www.kck.usm.my/mpsu/>

Finally please do supply the projects listing for your unit – we are trying to make central database of investigators so we can link researchers allowing for the sharing of protocols and questionnaires.

6th INOPSU Conference

Provisional Date 7th -8th October 2010

Venue Dublin – Republic of Ireland

• **New surveillance systems launched**

Child and Adolescent Psychiatry Surveillance System (CAPSS) was launched in May. Based at the Royal College of Psychiatry (UK) surveillance on conversion disorder and bipolar disorder will be underway in September. For details www.rcpsych.ac.uk/capss

Scottish Paediatric Surveillance Unit. The Scottish Paediatric Society has launched this new initiative in order to survey more common disorders seen in Scotland. Following a similar methodology as the BPSU but using on-line reporting the first e-card is to go out in September and will contain conditions such as adverse drug reactions; incidence of vitamin d deficiency and rickets, straddle injury, inflammatory bowel disease and coeliac disease, For details <http://www.scotpsu.co.uk/>

Australasian Maternal Outcomes Surveillance System (AMOSS) was launched on 24th of June 2009 and is established as a national system to study a range of serious, but rare obstetric complications and disorders of pregnancy, which are thought to contribute significantly to the burden of maternal morbidity. For details <http://www.npsu.unsw.edu.au/NPSUweb.nsf/page/AMOSS>

Paediatric Active Enhanced Disease Surveillance (PAEDS) was developed by APSU in collaboration with the National Centre for Immunization Research and Surveillance (NCIRS). PAEDS provides a hospital based surveillance system with active

case finding by specialist surveillance nurses. PAEDS is currently running in 4 tertiary children's hospitals in 4 states of Australia. PAEDS currently monitors for Acute Flaccid Paralysis, Severe Complications of Varicella, and Intussusception. In addition, funding from the National Health and Medical Research Council will support surveillance through the PAEDS system for all hospitalisations of influenza in children aged < 15 years during the Australian influenza season.

- **National interest in INOPSU activities**

INOPSU; On behalf of INOPSU the Canadian surveillance programme presented an INOPSU poster at the 20th European Society of Paediatric and Neonatal Intensive Care (ESPNIC) Congress in Verona Italy. Interest from several national delegates in the work of INOPSU was shown. As we know Italy and Poland have shown particular interest but so have clinicians from Russia, Romania and Mexico. Whilst Argentine paediatricians have asked if they can join INOPSU as an associate member

- **Recent publications**

APSU:

1. Madden S, Morris A, Zurynski Y et al. Burden of eating disorders in 5-13 year old children in Australia. [MJA 2009. 190; 410-414](#)
2. McDonald A, Zurynski Y et al. Perinatal exposure to HIV among children born in Australia, 1982–2006. [MJA 2009. 190; 416-420](#)

BPSU: Click [here](#) for the BPSU annual report 2008-09

1. Salotti J A, Nanduri V, Pearce M S, Parker L, Lynn R, Windebank K P. Incidence and clinical features of Langerhans cell histiocytosis in the UK and Ireland. [Arch Dis Child; May 2009; 94: 376 – 380.](#)
2. Teo S S S, Riordan A, Alfaham M, Clark J, Evans M R, Sharland M, Novelli V, Watson J M, Sonnenberg P, Hayward A, Moore-Gillon J, Shingadia D, and for the British Paediatric Surveillance Unit Childhood Tuberculosis Study Group Tuberculosis in the United Kingdom and Republic of Ireland. [Arch Dis Child; Apr 2009; 94: 263 - 267.](#)
3. Shield JP, Lynn R, Wan KC, Haines L, Barrett TG. Management and 1 year outcome for UK children with type 2 diabetes. [Arch Dis Child; 2009 Mar; 94\(3\):206-9.](#)
4. Judd A, Ferrand R, Jungmann E, Foster C, Masters J, Rice B, Lyall H, Tookey P, Prime K. Vertically acquired HIV diagnosed in adolescence and early adulthood in the United Kingdom and Ireland: findings from national surveillance. [HIV Medicine 2009; 10:253-256.](#)

CPSP: Click [here](#) for the CPSP annual report 2008

- **New INoPSU studies**

BPSU: Autumn sees the commencement of a study into [CNS inflammatory demyelination](#). Studies recently approved include neonatal meningitis and lead in children.

Rare disease news

- **Conferences**

British Paediatric Surveillance Unit conference was successfully held on 3rd March 2009 at the Royal Institute of British Architecture. Attended by over 90 clinicians from the UK and abroad presentations on the following themes were given; infectious disease in children; informing policy and practice; developing partnerships.

- **Public/Patient Involvement**

As part of her Creswick Fellowship, Yvonne Zurynski of the APSU has visited patient organisations for people affected by rare diseases: [Contact-a-Family](#); [INVOLVE](#); [Rare Diseases UK](#) and [Eurordis](#), and the rare diseases information service for clinicians, [Orphanet](#). Patients affected by rare diseases and their clinicians need information about the disease, parent support groups, and access to medical and social services. PSU's are well placed to improve availability of information on rare diseases that is accessible to patients and the public. APSU will endeavour to provide patient accessible summaries for each condition studied in the future, including a summary of the condition, support groups if these exist, and any educational opportunities for parents. The BPSU has already begun the process of providing disease summaries for the public. Orphanet has developed an educational program



on rare diseases that is included in the medical curriculum in France to raise awareness of rare diseases among future clinicians and to inform the of databases and search tools they may need when faced with diagnosing and managing people with rare diseases.