

# News Release

## BRITISH PAEDIATRIC SURVEILLANCE UNIT 19th ANNUAL REPORT

### BRITISH ISLES - WORLD LEADER IN RARE CHILDHOOD DISEASE SURVEILLANCE

Rare diseases are, paradoxically, an important cause of illness and death in childhood in the Western world. Although individually uncommon, together they number thousands. The difficulty for doctors recognising rare conditions can hold back important research and delay diagnosis increasing the risk of preventable complications or even death. In 1986 the United Kingdom and the Republic of Ireland collaborated in the development of the then British Paediatric Surveillance Unit (BPSU) to address the problems of identifying a significant number of cases of a rare disorder. The Unit makes it possible for researchers to undertake surveys of **rare disorders** in children.

Over 60 studies of rare disorders have been undertaken including HIV/AIDS, Reye's syndrome, Kawasaki disease and vitamin K deficiency bleeding in the newborn, haemophilus influenzae b and Group b streptococcal disease. The importance of the BPSU to public health continues to be recognised by the DoH through the receipt of continued funding support.

As Professor Liam Donaldson, the Chief Medical Officer recently stated, *"it is a matter of pride for this country that the innovative and scrupulous epidemiology of the BPSU has been emulated by several other countries in Europe and beyond"*.

#### **Amongst other major findings the 19h Annual Report highlighted:-**

- Identification of 6 cases of variant CJD in the paediatric population, though none in the past year.
- Though the prevalence of HIV infection in pregnant women is rising the proportion of infants who are infected is declining
- 376 children have been confirmed with TB. Rates are highest in London
- A study on non-type 1 diabetes suggests that the level of obesity related diabetes is now affecting children in greater numbers. 74 cases have been identified 80% are obesity related
- A study on neonatal herpes simplex virus points to a rise in incidence

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#### NOTES TO EDITORS

1. The BPSU began its work in June 1986, and represents the efforts of paediatricians in the United Kingdom and the Republic of Ireland. The Unit enables paediatricians to participate in the surveillance of infections and infection-related conditions and promotes the study of uncommon disorders. It provides a mechanism by which new diseases can be detected, monitored and investigated swiftly.
2. Several agencies collaborate in the system: the Royal College of Paediatrics and Child Health which works with the Health Protection Agency (formerly the Public Health Laboratory Service, Communicable Disease Surveillance Centre), and the Centre for Paediatric Epidemiology and Biostatistics at the Institute of Child Health, University of London, the Scottish Centre for Infection and Environmental Health in Glasgow, which administers the scheme in Scotland, and the Faculty of Paediatrics of the Royal College of Physicians (Ireland).

The current chairman of the BPSU Executive is Professor Michael Preece, Institute of Child Health (tel:0207 905 2622).

3. Participants in the reporting system include 2500 consultant paediatricians who are members of the RCPCH or the Faculty of Paediatrics of the Royal College of Physicians of Ireland. Individual surveys also involve other doctors: including pathologists, haematologists and paediatric surgeons.
4. The Unit does not undertake surveys itself but facilitates surveys from teams around the country. Conditions currently under surveillance are HIV/AIDS; congenital rubella; progressive intellectual and neurological degeneration; congenital toxoplasmosis; severe hyperbilirubinaemia in the newborn, Langerhans cell Histiocytosis, medium chain acyl CoA dehydrogenase deficiency, eating disorders in children under 13 years.
5. All 2500 participants are sent a report card and a set of instructions each month, on which the disorders under surveillance are listed. Respondents are asked to return the card to the surveillance unit office each month, reporting the number of cases of each disorder seen in the preceding month. Over 92% of paediatricians do so each month. The relevant surveillance team then follows up case reports.
6. Enquiries about particular surveys should be directed to the appropriate researcher, details in the annual report or contact Mr Richard Lynn, BPSU Scientific Coordinator, telephone and fax as above.