

News Release

BRITISH PAEDIATRIC SURVEILLANCE UNIT 15th 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 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.

Celebrating its 15th year of surveillance this small but effective British surveillance system has had a major impact on child health. As Professor Liam Donaldson, the Chief Medical Officer states in his acknowledgement, *"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"*.

Over 45 rare disorders have been undertaken including HIV/AIDS, Munchausen syndrome by proxy, Kawasaki disease and vitamin K deficiency bleeding in the newborn. The importance of the BPSU to public health has recently been further recognised by the DH through the receipt of a further three year grant.

Highlights in the 15th Annual Report include:-

- report of a study which has led to the identification of 4 cases of variant CJD in the paediatric population
- quantifying the link between recent *E.coli* O157 infection outbreaks and haemolytic uraemic syndrome in children
- the validation of the mass measles rubella vaccination campaign showing a decrease in congenital rubella and SSPE (a degenerative brain disease due to the measles virus).
- the UK *Haemophilus influenzae* b vaccination policy has dramatically reduced invasive Hib disease including meningitis and septicaemia in the UK and Ireland
- identification of two distinct groups of children developing group b streptococcal disease
- the Reye's survey vindicates the public health action taken public health action taken in advising against use of aspirin in children under 12 in 1986

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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 Public Health Laboratory Service (PHLS), (Communicable Disease Surveillance Centre), and the Department of Epidemiology at the Institute of Child Health, University of London (ICH(L)) 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 Dr Chris Verity, Addenbrooke's Hospital, Cambridge, CB2 (tel: 01223 216662).

3. Participants in the reporting system include 2100 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, encephalitis in under threes, progressive intellectual and neurological degeneration, subacute sclerosing panencephalitis, vitamin K deficiency bleeding, severe internal abdominal injuries due to child abuse, cerebral vascular disease/stroke in childhood, congenital cytomegalovirus and venous/arterial thrombosis.
5. All 2100 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 93% 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.