BRITISH PAEDIATRIC SURVEILLANCE UNIT
ROYAL COLLEGE OF PAEDIATRICS & CHILD HEALTH
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REGISTERED CHARITY No. 1057744

News Release

BRITISH PAEDIATRIC SURVEILLANCE UNIT
18th 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 50 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 18th Annual Report highlighted:-

- Identification of 6 cases of variant CJD in the paediatric population, though none in the past year.
- The rise in paediatric HIV in the British Isles in the past year
- 63 children have been confirmed with TB in the first 4 months of a 13 month study.
- The continuing need to monitor congenital rubella whose incidence may increase given the recent fall in the MMR uptake
- 103 cases of severe complications to varicella (chickenpox) have been reported in the past year.

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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 2400 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 complications of varicella (chickenpox); severe hyperbilirubinaemia in the newborn, Langerhans cell histiocytosis and medium chain acyl CoA dehydrogenase deficiency..

5. All 2400 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.

15/10/04 ENDS