

Where can I learn about the BPSU?

As well as leaflets like this one, we publish annual and quarterly reports. These are freely available through our website <http://bpsu.inopsu.com>

The BPSU works closely with parent support groups and organisations like Contact a Family, the national umbrella organisation for rare childhood disorder support groups. (Contact on 020 7608 8700 or <http://www.cafamily.org.uk> for more details)

The BPSU has had a major impact in helping children with rare disorders

Francine Bates
Chief Executive, Contact a Family

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

Professor Liam Donaldson
Chief Medical Officer

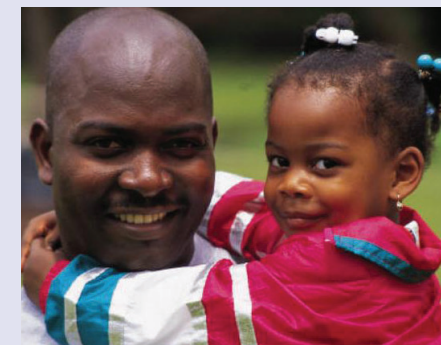


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British Paediatric Surveillance Unit

Investigating rare childhood conditions for the future health of the nation



A public information leaflet

What is the British Paediatric Surveillance Unit (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, the Health Protection Agency and the Institute of Child Health (London).

Why is the unit needed?

Rare conditions and infections are a serious cause of illness and disability. Sadly children may die from these rare conditions.

Although the individual condition may occur rarely, because there are thousands of these types of condition, the numbers of families affected is as great as the number of families affected by common illnesses.

For these rare conditions, it is necessary to conduct national studies to provide sufficient cases for meaningful results to be produced.

Studying rare conditions through the BPSU can make doctors more aware of such conditions and how to diagnose them, which provides more effective help and support to families.

What does the BPSU do?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by the particular disease or condition each year - this is called epidemiological surveillance.

Doctors can also gather information about all the cases of a particular rare condition so they can begin to understand what might have caused it and how to diagnose and treat.

How does the BPSU work?

Each month the unit sends a distinctive orange card to over 2400 consultant paediatricians; the card lists the rare conditions currently being studied.

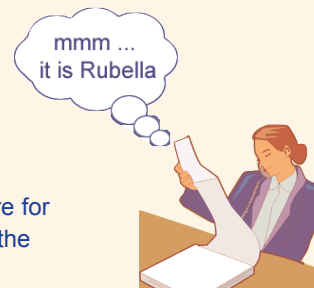


If a doctor has seen a child affected by one of these conditions they tick a box on the card and return it to BPSU.

British Paediatric Surveillance Unit Report Card

NOTHING TO REPORT	Month / Year
Specify in box number of cases seen	CODE No []
HIV & AIDS	
Congenital Rubella	
Stroke in Childhood	
Diabetes	
Neonatal Meningitis	
Childhood Tuberculosis	
Severe Visual Impairment / Blindness	
Drowning and Near Drowning	
Neonatal Herpes Simplex virus infection	

On receiving the card, the BPSU informs the investigation team, who send the reporting doctor a short confidential questionnaire for more information about the affected child.



BPSU researchers **never** contact families or children and surveillance studies don't ever affect a child's treatment.

The purpose is **ONLY** to collect information to learn more about the condition.

What has the BPSU achieved?

Public health impact

The BPSU has now helped to undertake surveys of over 60 rare conditions which may affect children.

It has monitored outcomes of national immunisation programmes by undertaking surveys of:

- congenital rubella
- polio (acute flaccid paralysis) and
- failure of vaccines eg Hib (*Haemophilus influenzae type b*)

Government bodies and other organisations use the evidence provided by BPSU to inform their response to public health issues, eg:

- confirming the safety of giving birth in water.
- assessing the impact of changing vitamin K administration in the newborn.
- monitoring the number of instances of infectious diseases such as vCJD, HIV / AIDS and tuberculosis
- providing evidence that aspirin may be harmful to children

Educating doctors

BPSU studies have resulted in over 300 presentations and scientific articles.

Internationally

This system is now used in 14 countries across the world.