

BRITISH PAEDIATRIC SURVEILLANCE UNIT



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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).

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.

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.

HOW DOES THE BPSU WORK?

Each month the unit sends a distinctive orange card to over 3200 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.

WHAT HAS THE BPSU ACHIEVED?

PUBLIC HEALTH IMPACT

The BPSU has now helped to undertake surveys of over 90 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

(From the BPSU Public Information Leaflet –'Investigating rare childhood conditions for the future health of the nation')

For further information contact:
British Paediatric Surveillance Unit
Royal College of Paediatrics & Child Health
5-11 Theobalds Road, London WC1X 8SH
Tel: +44 (0) 207 0926173 / 74
E-Mail: bpsu@rcpch.ac.uk

Website: <http://www.rcpch.ac.uk/bpsu> 4

PUBLIC INFORMATION SHEET

KAWASAKI DISEASE

INFORMING BETTER DIAGNOSIS, TREATMENT AND MANAGEMENT OF CHILDREN WITH KAWASAKI DISEASE

WHAT IS KAWASAKI DISEASE?

Kawasaki disease is a rare disease affecting children, usually between the ages of 1-5. It presents with a fever lasting for more than 5 days and also the children may have a rash, swollen glands in the neck, red fingers, red cracked and dry lips and red eyes. The cause of the disease is not known, but treatment is given to reduce the inflammation, with intravenous antibodies and high dose aspirin. Many parts of the body can be affected, especially the heart.

HOW IS IT DIAGNOSED?

Kawasaki disease is diagnosed by the presence of fever for more than 5 days, plus 4 of the following: rash, swollen glands, red eyes, red and cracked lips, red or swollen fingers.

TREATMENT

This is by giving of liquid antibody directly into a vein via a drip.

WHY IS IT TREATED?

If treatment starts early, then many of the complications can be reduced, especially of heart disease.

THE STUDY OF KAWASAKI DISEASE

The treatment and management of children with Kawasaki disease is fairly consistent even though the condition is quite rare in childhood.

This study has been designed to examine the onset and appearance of symptoms in children, the timing of investigations, and treatment and their relationship with complications which appear within thirty days. This is with the aim of improving understanding of the condition and the effect of the timing of treatment on outcomes.

The British Paediatric Surveillance Unit (BPSU) is supporting this study (see back page of leaflet) and we hope this information leaflet provides you with the necessary information about the study.

WHERE IS THIS STUDY HAPPENING

The study is being led by Bristol Royal Hospital for Children, working with hospitals in London and Oxford and will be taking place in all hospitals across the United Kingdom and the Republic of Ireland.

HOW LONG WILL THE STUDY GO ON FOR?

The study will continue for 13 months.

HOW WILL THE INFORMATION BE COLLECTED?

The doctors caring for children who develop Kawasaki disease will fill in a questionnaire and send this anonymous information to the study investigators in Bristol. They will also provide details of the child's progress, one year later.

Through analysing this information we hope to increase understanding of the causes and development of Kawasaki disease and improve treatment.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS

Information collected will not identify any individual and confidentiality will be maintained at all times.

By collecting the information about children who develop Kawasaki Disease it is hoped to increase understanding of the condition and help improve treatment for individual patients.

WHO SHOULD BE CONTACTED IF YOU HAVE ANY QUESTIONS ABOUT THIS STUDY?

Please contact the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, London (see over page).