

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, Public Health England and the University College London- Institute Of Child Health.

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, condition or treatment each year - this is called epidemiological surveillance. Researchers can 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. BPSU studies can benefit future patients with rare conditions.

How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialists; the card lists the rare conditions currently being studied. If any doctor has seen a child affected by one of these conditions they tick a box on the card and send it back. The BPSU informs the research team who then send the doctor a short confidential questionnaire asking for more information. Researchers are not told the names and addresses of patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 100 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.

For further information contact:

British Paediatric Surveillance Unit, Royal College of Paediatrics and Child Health, 5-11 Theobalds Road, London, WC1X 8SH,

T: +44 (0) 207 092 6173/4

Email: bpsu@rcpch.ac.uk Website: www.rcpch.ac.uk/bpsu/scarf



BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information Sheet

SURVEILLANCE OF CHILDHOOD ACUTE RHEUMATIC FEVER IN CHILDREN & YOUNG PEOPLE ≤16 YEARS OF AGE IN THE UK AND ROI

Surveillance of Childhood Acute Rheumatic Fever

This leaflet provides information about a new study of Acute Rheumatic Fever (ARF). It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is Acute Rheumatic Fever?

Acute rheumatic fever (ARF) is an illness, which happens as a result of the body reacting to an infection with a bacterium called group A streptococcus usually in the form of a sore throat. It can cause swelling or inflammation in certain parts of the body. This can include joint swelling and pain, a skin rash, abnormal movements and in some cases swelling of layers within the heart that can in extreme cases make you breathless. In the long term it can also lead to damage of certain parts of the heart, which may require medication or surgery and in a few severe cases heart failure or early death. This damage is made more likely with exposure to group A Streptococcus so identified patients are started on preventative antibiotics.

Why does Acute Rheumatic Fever develop?

It is unknown exactly why certain people develop this illness but it is more common in children and young adults. It is also much more common in developing countries.

What are the aims of this study?

There is much information about this illness from the developing world. It remains rare in developed countries such as the UK and it is therefore difficult to see whether the pattern of the illness is changing. The aim of the study is to look at how ARF affects children aged 16 or under in the UK and Republic of Ireland (ROI) today. We want to see the pattern of illness it produces and to see if it differs from the pattern of illness that is seen in developing countries or in the UK and ROI previously.

How will the information be collected?

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

How will the information be used?

British Paediatric Surveillance Unit (BPSU) researchers do not contact families or children with the condition. Children with ARF will continue to get the normal standard of care and treatment from their doctors.

We hope that this study will have benefits for future children with the condition by providing us with more information on how many children are affected by this condition.

Data collected on young people with SCARF will help us to improve our understanding of the current problems associated with this condition. This will help shape future approaches to preventing and managing the condition. All data collected will be held securely and confidentiality maintained at all times.

The NHS uses medical records for audit or research to improve future health and care. Hospitals and health professionals record when you do not want your child's notes to be used for audit or research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If so, their data will not be used in BPSU studies.

Where is this study happening?

We are collecting data from doctors in the UK and ROI. The analysis will be done by the team in Birmingham Children's Hospital

How long will the study go on for?

We will collect data over a 13 month period.

Who is funding this study?

This study is being funded by the BPSU Sir Peter Tizard Bursary

Who to contact if you have any questions

Please contact the principal investigator

Dr Mary Salama, Department of General Paediatrics, Birmingham Children's Hospital, Steelhouse Lane, Birmingham B4 6SS

Tel: 0121 333 8163; **Fax:** 0121 3338191; **Email:** scarf@bch.nhs.uk