

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 Public Health England and the University College Of 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 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. 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 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:

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Alder Hey Children's 
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Public Information Leaflet

Juvenile-onset Systemic Lupus Erythematosus

This leaflet provides information about a new study of Juvenile-onset Systemic Lupus Erythematosus (JSLE). 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.

What is JSLE?

JSLE or 'childhood lupus' is a rare disease where the immune system attacks many parts of the body. JSLE can be very variable in how it presents, with some children having a mild disease and others having a very severe disease (e.g. developing kidney failure or brain abnormalities).

Why does JSLE develop?

We don't know exactly why JSLE develops. It is likely to be a complicated combination of genetic and environmental factors.

What are the aims of this study?

We don't know how many children and young people in the UK and Ireland develop JSLE. This study will help us understand how many children are affected by JSLE and which medical teams look after them.

Children with JSLE present with different features and it can be difficult to classify children with JSLE. Classification criteria are important to help doctors diagnose JSLE and to help research better treatments for JSLE. We will look at what features are present, and how well the classification criteria we have for adults with lupus work in children with JSLE.

How will the information be collected?

The doctors caring for patients who are diagnosed with JSLE during the study will fill in a questionnaire. They will send this information to the study team in Liverpool. They will then fill in another questionnaire one year later about the child's progress.

How will the information be used?

BPSU researchers do not contact the children or families with the condition. Cases that are reported are sent to the research team without any names or addresses. All information that is collected will be confidential and stored securely.

We hope that the information will help us to look after children and young people with JSLE better, for example through designing better healthcare services to make sure all patients have access to the best care.

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 information from doctors in the UK and Ireland. The study team are based in Liverpool and all the results will be analysed here.

How long will the study go on for?

We will ask doctors to report any new cases of JSLE over a 25 month period. We will then send them a questionnaire one year after they made the diagnosis. The study will therefore last 3 years in total.

Who is funding this study?

This study is being funded by the BPSU Sir Peter Tizard Bursary and Lupus UK.

Who to contact if you have any questions

Please contact the study team:

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