

## 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 University 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 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.

### 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](mailto:bpsu@rcpch.ac.uk) Website: [www.rcpch.ac.uk/bpsu](http://www.rcpch.ac.uk/bpsu)

15.3.2015 V5. Leaflet expiry date 31/5/2017



## BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information Leaflet

### Behçet's syndrome in children and young people <16 years of age in the UK & ROI

This leaflet provides information about a new study of Behçet's syndrome in children and young people in the UK. 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 Behçet's syndrome?

Behçet's syndrome is a rare condition which can cause inflammation in many parts of the body. In particular, it can cause repeated attacks of mouth and/or genital ulcers (sores), which can sometimes occur with skin rashes, tiredness, joint pains, tummy pains, headaches or eye problems. Behçet's syndrome can affect children although we currently do not know how many children are affected in the UK.

### Why does Behçet's syndrome develop?

We don't know why Behçet's syndrome develops or how many children are affected by it in the UK.

## What are the aims of this study?

- 1) To understand how many children in the UK are affected by Behçet's syndrome
- 2) To understand how Behçet's syndrome affects children
- 3) To understand who is involved in the medical care and treatment of children with this condition
- 4) To see if there is a delay in children receiving care from doctors with expertise in this condition

## How will the information be collected?

This study is being supported by the British Paediatric Surveillance Unit (BPSU) as well as the British Society of Paediatric Dermatologists. Every month, paediatricians and paediatric dermatologists will be asked if they have seen any possible cases of Behçet's syndrome. If they have, they will be asked to fill in a short confidential questionnaire about the child. The study team will collect and analyse all the information from children with Behçet's syndrome over a 13 month period.

We will also be asking a short follow-up questionnaire one year on.

The study team are not told the names or addresses of children. Families are not contacted by the study team.

Children and families with Behçet's syndrome have been involved in designing the study and making sure information about the study is easy to understand. The Behçet's Syndrome Society has helped us too.

## How will the information be used?

BPSU studies do not contact families or children with the condition. The care and treatment of children with Behçet's syndrome will not be affected by this study.

Cases that are reported are done so without anyone being able to identify the child involved. All information collected is confidential.

We hope that the results of this study will have benefits for future children with the condition by providing us with more information on how many children are affected and how Behçet's syndrome makes them ill.

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 would also not be used in BPSU studies.

## Where is this study happening?

The study is being led Dr Clare Pain from Alder Hey Children's NHS Foundation Trust and will be happening in all hospitals in the UK and Ireland that see children with this condition.

## How long will the study go on for?

For 25 months, then there will be a follow-up study one year later.

## Who is funding this study?

The Behçet's Syndrome Society are part funding the study and will remain involved in the study including disseminating results of the study to families and children with this condition. Alder Hey Children's Charity and the study investigators are also funding the study

## Who to contact if you have any questions

Please contact the principal investigator:

Dr Clare Pain, Department of Rheumatology, Alder Hey Children's Hospital, Eaton Road, Liverpool L12 2AP

Tel: 0151 282 4521 Email: [behcet@alderhey.nhs.uk](mailto:behcet@alderhey.nhs.uk)

## Further website information

**BPSU:** <http://www.rcpch.ac.uk/bpsu/bht>

**Behçet's Syndrome Society:** <http://behcets.org.uk/>