

## 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 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:

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## BRITISH PAEDIATRIC SURVEILLANCE UNIT Public Information Sheet

### SURVEILLANCE OF BRITISH CHILDHOOD VISUAL IMPAIRMENT AND BLINDNESS STUDY 2 (BCVIS 2)

This leaflet provides information about a new study of visual impairment and blindness amongst children. It describes the condition being studied, 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 visual impairment / blindness?

Visual impairment or blindness are the terms used when a person has significant sight loss caused by illness or injury that cannot be corrected using glasses or contact lenses. In most affected children, the condition is present from the first years of life.

### Why does visual impairment / blindness develop?

There are many causes which involve diseases of the eye itself, or the areas in the brain which process vision.

### What are the aims of this study?

To understand how many new cases of visual impairment there are amongst children each year, what has caused their impairment, how severe their impairment is and if there are any particular groups of children who are more likely to be affected. We also hope to understand what

happens to the health and development of children in the first year after they are found to have visual impairment.

### **What will the study mean for me and my child?**

There is nothing for you to do. This study will only involve information which your child's doctor records as part of routine care. There will be no impact on the care your child receives.

### **How will the information be collected?**

The doctors looking after children with visual impairment will share relevant information with the research team in line with data protection law (see below).

### **How will the information be used?**

BPSU researchers do not contact families or children with the condition. Children with visual impairment and blindness will continue to get the normal standard of care and treatment from their doctors.

This study will help to improve services, and plan future research and policies for, affected children. There are no physical risks for patients. As we will be collecting information we will make sure that we keep the data securely protected. A law (Data Protection Act 1998) has been put in place to make sure that your data cannot be misused. An ethics committee, made up of members of the public and professionals, has assessed the risks and benefits of this study and approved it.

When people can be recognised by their data, only specific people can see the information and in a secure place.

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.

### **What do I do if I do not want to be part of the study, or do not want my child to be part of the study?**

Hospitals and health professionals record when you do not want your child's notes to be used for research so you must always let your child's doctors know if you do not wish their medical notes to be used for research.

### **Where is this study happening?**

The study is happening across England, Northern Ireland, Scotland, and Wales

### **How long will the study go on for?**

The study will be identifying new cases of children with visual impairment over a one year period

### **Where will the results be published?**

Once the study is completed, you will be able to find the results on the BPSU website: [www.rcpch.ac.uk/bpsu](http://www.rcpch.ac.uk/bpsu)

### **Who is funding this study?**

Fight for Sight, the UK's biggest sight related charity, who fully and independently reviewed the study.

### **Who to contact if you have any questions**

For further information, please contact:

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