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 and is a partnership between the Royal College of Paediatrics and Child Health, Public Health England, and the Institute of Child Health at Great Ormond St Hospital and University College London.

What does the BPSU do?

It allows doctors and researchers to find out more about rare or uncommon conditions or infections that affect children in the UK and the Republic of Ireland. This includes finding out how many children have the condition and understanding more about the problems they have so that diagnosis and treatment can be improved. Future patients with rare conditions will benefit.

How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialist doctors; the card lists the conditions currently being studied. If any doctor has seen a child affected by one of these conditions, then 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 about health and care. Researchers are not told the names and addresses of any patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has helped investigators to undertake surveys of over 100 rare conditions that may affect children. These studies have helped to increase understanding of why the conditions occur, and guided improvements in screening, treatments and care.

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Microcephaly in Infants

Improving understanding of children’s development and care needs.

This leaflet provides information about a new study of microcephaly – or small head size – in babies under one year of age in the UK and Ireland.

It provides 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 microcephaly?

Microcephaly means ‘small head size’. It describes babies who are born with a head that is much smaller than expected. Some babies with microcephaly also have poor brain growth. It is unclear how many babies have microcephaly, how severe it is, and what health and development problems these babies have.

Why does microcephaly develop?

Microcephaly may occur for many different reasons, such as infections or illnesses in the mother during pregnancy, or a genetic problem. Two important infections in the mother that may cause microcephaly are rubella (German measles) and Zika virus. Often the reason that a baby has microcephaly is not known.
What are the aims of this study?

This study will find out how many babies in the UK and Ireland are born with microcephaly during one year. We will collect information about how seriously this affects babies. For example, we will find out if babies have problems with brain development, vision and/or hearing, or other health problems.

This will help us to understand the impact of microcephaly on children’s health and development, how they will cope at school and their family life. It will help to show whether the right services and care are being offered to children, and will guide future changes in treatment and care.

Importantly, it will allow us to monitor changes in the number of babies with microcephaly for example due to Zika virus infection.

How will information be collected?

Paediatricians will be asked each month to report the number of babies with a new diagnosis of microcephaly. All doctors who report a case will be sent a confidential questionnaire to collect more details about the child’s health and development. The questionnaire can be filled in using information already in the child’s hospital notes.

Children with microcephaly will continue to get the normal standard of care and treatment from their doctors.

How will the information be used?

The information that is collected will be held securely and confidentiality will be maintained at all times. Researchers are not told the names and addresses of any patients, and families are not contacted.

Information about each child, such as NHS or CHI number, date of birth, hospital number and the first half of the postcode, will be given by the child’s paediatrician to the study team. This allows the study team to make sure they are not receiving several questionnaires about one child. The information is only used by the study team and it is stored securely to stop anyone else from seeing it.

What if I do not want my child to be involved?

Hospitals and health professionals will record if parents do not want their child’s notes to be used for audit or research so you must tell your doctor if you do not want your child’s notes used. If you do this, then your child’s notes will not be used in any BPSU study.

Where is this study happening?

The study team is based at the Institute of Child Health at Great Ormond St Hospital and University College London. The study will involve children with microcephaly across the UK and Ireland.

How long will the study go on for?

The study will continue up to school age. Information on new babies who are found to have microcephaly will be collected for one year. Information will also be collected from doctors about the health and development of these babies when they are one year old and two years old.

We will also use some limited information, such as the NHS number and date of birth, to track babies’ health and development up to 11 years of age using health and education data that is collected routinely on all children. For example, we may wish to find out how many times children go into hospital, or how many children have a statement of educational needs when they enter school.

Who is funding this study?

The study is being funded by Great Ormond Street Hospital Children’s Charity (GOSHCC).

Who to contact if you have any questions:

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