BRITISH PAEDIATRIC SURVEILLANCE UNIT

WHAT IS THE BRITISH PAEDIATRIC SURVEILLANCE UNIT (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions or treatments in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, the Health Protection Agency and the Institute of Child Health (London).

WHAT DOES THE BPSU DO?

It allows doctors and researchers to find out how many children in the UK 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.

On receiving the card, the BPSU informs the study team, who send the reporting doctor a confidential anonymised questionnaire to gather more information about the child. BPSU researchers never contact families or children and surveillance studies don't affect a child's treatment. The purpose is ONLY to collect information to learn more about the condition.

HOW DOES THE BPSU WORK?

Each month the unit sends a distinctive orange card to over 3500 consultant Paediatricians. The card lists the rare conditions currently being studied.
If a doctor has seen a child affected by one of these conditions they tick a box on the card and return it to BPSU.

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 these conditions and the healthcare services needed to manage them.

For further information contact:
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Central Manchester University Hospitals NHS Foundation Trust
Surveillance of Rare Childhood Disease • BPSU •
NHS Blood and Transplant

BRITISH PAEDIATRIC SURVEILLANCE UNIT

Public Information Sheet

SURVEILLANCE OF NEONATAL EXCHANGE BLOOD TRANSFUSION IN UK & IRISH INFANTS ≤28 DAYS OF AGE

What is Neonatal Exchange Blood Transfusion?

Exchange Blood Transfusion (EBT) is a treatment that removes the maternal antibodies from the baby's bloodstream, which are causing the baby's red cells to break down, leading to low haemoglobin (anaemia) and high bilirubin (yellowish pigment found in bile, made by the liver) levels. EBT can help remove bilirubin from the body.

Why is a Neonatal Exchange Blood Transfusion performed?

Many babies develop a mild or moderate level of jaundice (a yellow colouring of the skin and eyes) in the newborn period, which if it requires treatment usually responds to this and is harmless. Some babies, however, develop particularly high levels of bilirubin (the substance which causes jaundice) in the newborn period. This occurs particularly if there is a blood group difference (and antibodies develop) between the mother's and the baby's blood. There are also other causes. Very high bilirubin levels can cause brain damage resulting in cerebral palsy and / or deafness and requires urgent treatment.

Raised levels of bilirubin can sometimes be treated with phototherapy (light treatment) but occasionally an additional treatment known as EBT is required.

Why is this study happening?

We need to obtain better evidence about the safety and effectiveness of this procedure. In the past, this procedure was much more common and most of the evidence for it was produced by looking back through case notes. We now need up-to-date information which can tell us more about how many new born babies receive EBT and what the current risks and side effects are.

Where is this study happening?

The study is being led by medical research staff at St. Mary's Hospital, Manchester, the Imperial College, University College and King's College Hospitals, London and will be taking place in all hospitals across the United Kingdom, Ireland and the Channel Islands.

How will information be collected and used?

Medical doctors in the UK, Republic of Ireland and the Channel Islands who are caring for babies who undergo an EBT will fill in a questionnaire giving information about the procedure itself, blood tests and any difficulties that there might have been during or after. The information will be sent to the study data analysis centre at NHS Blood and Transplant.

Information will not contain names but other information such as hospital and NHS number, date and time of birth, will be obtained. This information is needed to ascertain e.g. if a baby has been reported more than once and how old the baby was at the time of the EBT. The care and treatment babies receive will not change as a result of the information being collected in this study.

By collecting the information about babies who undergo an EBT it is hoped to increase understanding of the extent of the use of this procedure in the UK and Ireland, the potential risks associated with it, which may help to influence future development of better and safer ways of performing the procedure and the development of safer blood products.

How long will the study go on for?

The study will continue for 13 months.

Who should be contacted if you have any questions about this study or wish to opt out?

Please contact Dr Ruth Gottstein, Consultant Neonatologist, St. Mary's Hospital, Oxford Road Manchester M13 9WL; Tel: 0161 276 6857; Email: ruth.gottstein@cmft.nhs.uk or British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, London (see overleaf).

Who has funded the study?

NHS Blood and Transplant Trustees Fund & NICU Endowment Fund, St. Mary's Hospital, Manchester.

Further website information

BPSU -	http://www.rcphch.ac.uk/bpsu/ebt
NHS Blood and Transplant -	http://www.nhsbt.nhs.uk
NHS Central Manchester University Hospitals -	http://www.cmft.nhs.uk