

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 Institute of Child Health (London).

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. Patients can tell their own doctor if they do not want their NHS data to be used to audit the quality of care or for research.

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?

PUBLIC HEALTH IMPACT

The BPSU has now helped to undertake surveys of over 60 rare conditions which may affect children. These have helped to increase understanding of why these conditions occur and can help to provide better diagnoses and treatments.

(From the BPSU Public Information Leaflet – ‘Investigating rare childhood conditions for the future health of the nation’)

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BRITISH PAEDIATRIC SURVEILLANCE UNIT

SURGICAL LIGATION OF THE PATENT DUCTUS ARTERIOSUS IN PREMATURE INFANTS

**A UK-WIDE SURVEY OF PREMATURE BABIES WHO UNDERGO LIGATION OF
THE PATENT DUCTUS ARTERIOSUS BEFORE DISCHARGE HOME.**

PUBLIC INFORMATION SHEET

SURGICAL LIGATION OF THE PATENT DUCTUS ARTERIOSUS IN

PREMATURE INFANTS

BACKGROUND

WHAT IS THE DUCTUS ARTERIOSUS?

In the womb, the baby's circulation between the heart, lungs and the rest of the body is slightly different from after birth. One of the differences is a small vessel called the ductus arteriosus which allows blood to bypass the lungs while the baby is in the womb. Once the baby is born, and starts to breathe and use the lungs, the ductus arteriosus usually begins to close and closes within the first few hours.

WHAT IS A PATENT DUCTUS ARTERIOSUS (PDA)?

If a baby is born early or prematurely, before 37 weeks of pregnancy, the ductus arteriosus may not close. An open ductus arteriosus is called a patent ductus arteriosus (PDA).

WHAT ARE THE EFFECTS OF A PATENT DUCTUS ARTERIOSUS?

The abnormal flow of blood can lead to breathlessness, poor feeding and perhaps chronic damage or bleeding in the lungs. It can also cause damage to the gut and brain and affect vision. Some babies have only mild symptoms.

TREATMENT OF THE PATENT DUCTUS ARTERIOSUS

It can be difficult to know the best way of treating this condition. If there are no symptoms, treatment is not necessary and the baby can go home with outpatient follow up. If the heart is under pressure, medicines called diuretics can be used to decrease its workload. Medicines such as indomethacin or ibuprofen can be used to close the PDA. If medicines do not work or can't be given, the baby may need an operation to close the PDA. This is called surgical ligation of the ductus arteriosus.

WHAT IS SURGICAL LIGATION OF THE PDA?

The most common operation for closing the PDA involves making a small cut in the left side of the chest and placing a clip across the PDA.

THE STUDY

WHAT ARE THE AIMS OF THIS STUDY?

This study will collect information about premature babies who have an operation to tie or clip off (surgical ligation) the patent ductus arteriosus (PDA). Our aim is to improve understanding of which babies need this operation and how they progress after the operation. The British Paediatric Surveillance Unit (BPSU) is supporting this study (see back page of leaflet). This information leaflet provides more information about the study.

WHAT DOES THIS STUDY MEAN FOR BABIES WITH PDA?

This study will not change the care which premature babies with PDA currently receive. Doctors caring for premature babies who have a PDA ligation will complete a confidential questionnaire about each baby's medical condition before the operation and progress after the operation. The doctors will not give any babies' names or addresses to the researchers. All patient information will be held securely and patient confidentiality will be maintained at all times.

WHERE IS THIS STUDY HAPPENING?

The study will be taking place across the United Kingdom, Northern Ireland and the Channel Islands.

HOW LONG WILL IT GO ON FOR?

The study will start in <<insert date>> and continue for 13 months.

WHAT ARE THE RISKS AND BENEFITS?

This study will be useful in telling us more about the success of operations for PDA. The information should help us improve the care of premature babies with a PDA in future.

WHO SHOULD BE CONTACTED IF I HAVE ANY QUESTIONS ABOUT THIS STUDY?

Please contact the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, London (see over page).