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 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 or condition 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 3000 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 70 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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BRITISH PAEDIATRIC SURVEILLANCE UNIT

Public Information Sheet

UK SURVEILLANCE OF PRIMARY CONGENITAL HYPOTHYROIDISM IN CHILDREN

National Surveillance Study of Congenital Hypothyroidism in Children Aged up to Five Years of Age

WHAT IS CONGENITAL HYPOTHYROIDISM?

Congenital hypothyroidism is a disorder of the thyroid gland. The thyroid gland is normally found at the front of the neck and makes a hormone called thyroxine, which is needed for normal growth and development. If the thyroid gland does not produce enough thyroxine from birth, it is called *congenital hypothyroidism*. Babies with hypothyroidism may have feeding difficulties, sleepiness, constipation and jaundice. Hypothyroidism is treated by lifelong replacement of thyroxine given every day by mouth. If babies do not start treatment soon after birth, they may have problems with their mental development and growth.

WHO IS AFFECTED BY CONGENITAL HYPOTHYROIDISM?

About 175-210 babies are born each year in the UK.

HOW IS CONGENITAL HYPOTHYROIDISM DETECTED?

Most babies are detected by the newborn bloodspot (heel-prick) screening programme.

HOW IS CONGENITAL HYPOTHYROIDISM TREATED?

It is treated by lifelong replacement of thyroxine given every day by mouth, either as tablets or a liquid.

THE CONGENITAL HYPOTHYROIDISM SURVEILLANCE STUDY

From this study, we will find out how many newborn babies are diagnosed after a positive screening test and also how many children up to five years old are diagnosed because they show symptoms rather than through screening. Although screening was introduced in 1981, we do not know how successful the screening programme is.

We will also describe the features of babies and children when they are first diagnosed and what treatment they are given. We will follow children up one and two years after they are first diagnosed, to find out how healthy they are and if they have only had temporary thyroid problems.

This national study will provide useful information about the numbers of children with hypothyroidism, how many are found by newborn screening and whether children are offered appropriate treatment and care.

The British Paediatric Surveillance Unit (BPSU) is supporting this study (see back page of leaflet), as well as the British Society for Paediatric Endocrinology and Diabetes (BSPED), UK Newborn Screening Programme, UK Newborn Screening Laboratory Network and British Thyroid Foundation. The study will be taking place in all hospitals in England, Wales, Scotland and Northern Ireland.

STUDY TEAM

The study is based at the Institute of Child Health, London. Other study team members are from University College London, the Royal Victoria Hospital (Newcastle), the UK Newborn Screening Programme Centre and Birmingham Newborn Screening Laboratory.

HOW LONG WILL THE STUDY GO ON FOR?

The study will continue for three years.

HOW WILL INFORMATION BE COLLECTED?

The doctors looking after a child with hypothyroidism will send anonymous information to us about the diagnosis, condition and care of the child. More anonymous information will be collected at one and two years. Newborn screening laboratory directors will also be asked to report anonymously to the study team if they find any positive screening test results. We will not ask anything of parents or children.

WHAT ARE THE POSSIBLE RISKS AND BENEFITS OF THE STUDY?

Information collected will not identify any individual and confidentiality will be maintained at all times.

By collecting information about children up to five years of age who are diagnosed with congenital hypothyroidism, it is hoped to increase understanding of the condition and improve treatment and screening in future.

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

Please contact the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, London (see back page) or contact the study team at <<study contact details>>.

<<<study team logos>>>