

## 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 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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## BRITISH PAEDIATRIC SURVEILLANCE UNIT

### Public Information Sheet

## UK SURVEILLANCE OF ENTERO AND PARECHOVIRUS MENINGITIS IN BABIES LESS THAN 90 DAYS OF AGE

### What is Enterovirus and Parechovirus Meningitis?

Viruses are generally considered to cause less severe illnesses in babies compared with bacteria. However, in young babies, infections from viruses known as Enterovirus and Human Parechovirus (HPEV) can be as serious as bacterial infections. In most babies Enteroviruses and Human Parechovirus cause mild symptoms such as fever or rash which disappear after a short time. However, in some, these viruses may progress to more serious illnesses, including meningitis, multi organ failure, cerebral palsy and a very small number may die.

Recent advances in laboratory techniques have led to four-times the number of babies being diagnosed with Enterovirus and Parechovirus meningitis in England and Wales. This number is continuing to increase. At present, there are no guidelines for clinicians on when to test or how to look after babies suspected with enterovirus/HPEV meningitis and at the

moment there are no licensed antiviral medicines to treat such infections. There are many types of enterovirus and we do not know whether different ones cause more serious disease than others.

### **What are the aims of this study?**

The study will aim to find out how many babies aged less than 90 days are affected by these viruses. It will collect information about their symptoms, laboratory tests and the effects of the illness. The study will aim to improve our understanding of enterovirus and parechovirus meningitis and also the outcomes. We hope that our study will help increase awareness of this condition among paediatricians (children's specialists) and help develop national guidance on how to look after young babies suspected with enteroviral/HPeV meningitis. We hope that the results of this study will encourage further research, including the development of new antiviral medicines and vaccines.

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

Paediatricians will be asked to report any cases they have seen to the study team. They will then be asked to complete a questionnaire, which will be anonymised, to obtain clinical details about babies they have treated.

### **What are the possible risks and benefits?**

The major benefit of this study is for future families, to gain information to improve understanding and develop therapies to treat this illness. All information collected will be treated confidentially and no individual will be identified.

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

In the United Kingdom and Republic of Ireland. It has been approved by the NRES Committee London - Queen Square research ethics committee (Ref: 14/LO/0229).

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

One year, from July 2014 to July 2015

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

Paediatric Infectious Diseases Research Group, St George's University of London

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

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### **Further website information**

RCPCH/BPSU - [www.rcpch.ac.uk/bpsu/neoentero](http://www.rcpch.ac.uk/bpsu/neoentero)  
Meningitis Now - [www.meningitisnow.org](http://www.meningitisnow.org)  
Meningitis Research Foundation - [www.meningitis.org](http://www.meningitis.org)