

## 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, Public Health England and the University Of London- Institute Of Child Health.

## 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.

## 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?

The BPSU has now helped to undertake surveys of over 100 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

### For further information contact:

British Paediatric Surveillance Unit, Royal College of Paediatrics and Child Health, 5-11 Theobalds Road, London, WC1X 8SH,  
T: +44 (0) 207 092 6173/4  
Email: [bpsu@rcpch.ac.uk](mailto:bpsu@rcpch.ac.uk) Website: [www.rcpch.ac.uk/bpsu/sdp](http://www.rcpch.ac.uk/bpsu/sdp)

Version 3.0 (26/09/2016)



## BRITISH PAEDIATRIC SURVEILLANCE UNIT

### Public Information Leaflet

# Deaths in Children with Epilepsy (Excl. Scotland)

This leaflet provides information about a new study of deaths in children with epilepsy. It aims to provide 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 Epilepsy?

Epilepsy is a common condition, affecting more than 600,000 people in the UK. This means that almost one in every 100 people has the condition. It mainly affects the brain and causes repeated 'fits' or seizures. Epilepsy can start at any age, but it most often begins during childhood. For most people with epilepsy, treatment with medications called anti-epileptic drugs (AEDs) is recommended. These medications cannot cure epilepsy, but they are often very effective in controlling seizures.

## Why do some children with epilepsy die?

A common perception of parents first witnessing a seizure is that their child almost died, and a common fear is that their child might die if another seizure occurs. It is very rare for a child to die from a seizure. However, studies have shown that people with epilepsy, including children and young people, have a higher risk of death than people without epilepsy. Children with epilepsy may die from a number of causes including; complication of a seizure such as suffocation, injury, drowning, status epilepticus (a seizure which continues for a prolonged period or when convulsive seizures occur one after the other with no recovery between), a related underlying condition (e.g.

brain tumour), suicide or sudden unexplained death in epilepsy (SUDEP).

SUDEP is defined as death for no obvious reason in a person with epilepsy, and it is hard to predict. SUDEP happens in about one in every 1,000 people with epilepsy. There is no way of knowing who will be affected by SUDEP. The exact cause is not known and there may be no single explanation. Some people with epilepsy have a higher risk of SUDEP than others. The single most important risk factor is uncontrolled generalised tonic-clonic seizures. This is a type of seizure that causes the person to lose consciousness and the body goes stiff and then starts jerking.

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

The study will:

- Provide important information regarding the number of deaths in children (aged 0-16 years) with epilepsy in the UK
- Compare the differences between SUDEP and other causes of epilepsy deaths.
- Raise awareness of the increased risk of early death associated with epilepsy will help in improving medication compliance and engagement with clinical services.

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

All paediatric doctors will be asked every month how many deaths in children with epilepsy they have seen in the last month. The research team will then send the reporting doctor a short confidential questionnaire for more information about the affected child and family (mainly diagnosis, health problems and treatment). The researchers will not contact families. Information collected will not identify any individual and all data collected will be held securely confidentiality will be maintained at all times.

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

By collecting the information about children with epilepsy who have died, it is hoped to increase understanding of the extent of the problem among children in the UK. This will make it possible to target at risk groups more precisely and ensure that we can influence future public health policy and NHS practice. By working with groups such as Epilepsy Action ([www.epilepsy.org.uk](http://www.epilepsy.org.uk)), Epilepsy Research UK ([www.epilepsyresearch.org.uk](http://www.epilepsyresearch.org.uk)) and SUDEP Action ([www.sudep.org](http://www.sudep.org))

findings will be produced in patient friendly formats making the information accessible to a wide audience. This research will help health care providers, advocacy groups, and others interested in improving outcomes for children with epilepsy to work together to prevent complications associated with epilepsy and reduce their risk for premature death.

### **How to opt out of the research?**

The NHS uses medical records for research to improve future health and care. Hospitals and health professionals record when you do not want your child's notes to be used research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If this is the case, your child's data will not be used in BPSU studies.

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

The study is taking place in all hospitals across the United Kingdom (excl. Scotland), Ireland and the Channel Islands.

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

The study will take place over a 13 month period starting in October 2016.

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

This study is being funded by SUDEP Action ([www.sudep.org](http://www.sudep.org)).

### **Further information**

<b>BPSU:</b>	<a href="http://www.rcpch.ac.uk/bpsu/epilepsy">www.rcpch.ac.uk/bpsu/epilepsy</a>
<b>SUDEP Action:</b>	<a href="http://www.sudep.org">www.sudep.org</a>
<b>Epilepsy Action:</b>	<a href="http://www.epilepsy.org.uk">www.epilepsy.org.uk</a>
<b>Epilepsy Research UK:</b>	<a href="http://www.epilepsyresearch.org.uk">www.epilepsyresearch.org.uk</a>

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

Dr Omar Abdel-Mannan, NIHR Academic Clinical Fellow, Population, Policy and Practice Programme, UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH

**Tel:** 0771 774 7012

**Email:** [ich.bpsu.sudep@ucl.ac.uk](mailto:ich.bpsu.sudep@ucl.ac.uk)