

## 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.

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## BRITISH PAEDIATRIC SURVEILLANCE UNIT

### Public Information Leaflet

# Childhood Disintegrative Disorder

This leaflet provides information about a new study of Childhood Disintegrative Disorder using the BPSU and Child and Adolescent Psychiatry Surveillance System reporting schemes. 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 Childhood Disintegrative Disorder?

Childhood Disintegrative Disorder (or CDD for short; also known as "Heller's Syndrome") is a condition that affects the brain of previously healthy children, causing a decline in their abilities to communicate, socially interact, play, and do things for themselves, such that they appear to have a very severe form of Autism. CDD usually affects children at around the age of 3-5 years, but can occur earlier or later. The children affected are usually well and developing normally until the onset of the disorder, at which point parents usually notice a very sudden and rapid change in their abilities. Sadly, most affected children do not recover their previous abilities, and are dependent on support for the rest of their lives.

CDD is very rare, probably affecting only 1-2 per 100,000 children. At the moment, we do not know what causes this condition to occur, or how best to treat it. We do not even know how many new cases there are each year in the UK and Ireland. As such, we plan to undertake a nationwide study of CDD with the following aims in mind:

## What are the aims of this study?

- To find out how many new cases of CDD are seen in the UK and Ireland each year
- To describe the range of problems that children with CDD have, and whether any of these problems might help in predicting how severely a child may be affected
- To find out which tests (blood tests, genetic tests, brain scans, brain-wave tests) doctors request for children with CDD, and which of these tests have abnormal results
- To find out which treatments doctors are using for CDD at the moment
- To find out how children are 1 and 2 years after CDD started, and what support they are requiring at that stage

We hope that with all this information we will be able to advise on which services children and families affected by CDD need, and be able to provide better information to professionals supporting affected families so as to reduce some of the stress for those facing this devastating diagnosis.

## How will the information be collected?

Paediatricians and Child Psychiatrists who see children affected by CDD will complete a confidential questionnaire and return this to the study investigators in London. The questionnaire is anonymised and the child's identity will only be known to the doctor caring for them. Some identifiable information will however be disclosed outside of the care team: NHS number and Hospital number for de-duplication of cases and data linkage; gender, ethnicity and date of birth will be used for analysis of data by demographics.

This study is run through the British Paediatric Surveillance Unit (BPSU), and the Child and Adolescent Psychiatry Surveillance System (CAPSS).

## How will the information be used?

The collection of information will be done without the study team contacting the family of affected children; the child will receive the usual care and treatment from their team of health professionals. We hope that by collecting information on CDD we will have a better

understanding of CDD, which will help future children and families affected by it.

A summary of the findings of the study will be published on the web for the public to access, and through Autism related charities. We would also like to publish our findings in a medical journal, or present it at a medical conference. Families should be reassured that the collected data will be stored and analysed anonymously, so that it would not be possible to identify any particular child taking part from the data or any published information.

## 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 or psychiatrist 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, 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 November 2016 with follow up at one and two years.

## Who is funding this study?

Funding for the administrative costs of this study has been granted by The Shirley Foundation (<http://www.steveshirley.com/shirley-foundation/>).

## Further information

BPSU: <http://www.rcpch.ac.uk/bpsu/CDD>

Autistica UK: <https://www.autistica.org.uk>

## Who to contact if you have any questions?

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