**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 Great Ormond Street Institute of Child Health (University College 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 condition or condition each year ‐ this is called surveillance. Doctors can also collect information about children with a particular rare condition. This will help them to understand what might have caused the condition and how to manage it better. BPSU studies can help future children with a similar rare condition.

**How does the BPSU work?**

Each month the BPSU sends an online e-card to over 4,000 consultant paediatricians and specialist doctors. The card lists any rare conditions currently being studied. If any doctor has seen a child with one of these conditions, they tick a box on the card and send it back. The BPSU tells the research team who send the doctor a short confidential questionnaire asking for more information from the medical record. Researchers are not told the names and addresses of children, and families are not contacted.

**What has the BPSU achieved?**

The BPSU has now helped to undertake studies of over 120 rare conditions that affect children. These have helped to improve understanding of the rare conditions, such as why they occur and how to improve prevention, treatment and care.

**For further information about the BPSU 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](http://www.rcpch.ac.uk/bpsu)/

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**Public Information Leaflet**

**Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD)**

This leaflet provides information about a new study about ROHHAD.

**What is ROHHAD?**

ROHHAD is a rare condition which causes life-threatening obesity, trouble breathing at night, a wide range of hormone problems and an irregular heartbeat. Children often need masks and machines to breath at night, take hormone tablets and injections for the rest of their lives, as well as having a greater cancer risk. We do not know why children get this condition and as there is no single test for diagnosis, and it can take a long time for families to get a diagnosis. We do not yet know of any treatments that can cure the condition.

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

The aim of this study is to try to understand more about ROHHAD and the care that children receive to help improve care and outcomes for children living with ROHHAD. We think that more children have this condition than is currently recognised and this study will help to estimate how many children are affected by ROHHAD in the UK and Republic of Ireland.

We aim to understand more about how ROHHAD affects children and how they are being cared for. We hope that by finding out more about how the symptoms of ROHHAD may develop and through raising awareness, this study will help children to receive a diagnosis and treatment earlier. We also hope the results of this study will help to improve patient care by enabling us to recommend standardised care pathways. Therefore, this study could also help many children who may develop ROHHAD in the future. We will share our results from the study with as many people as possible to help improve how we care for children with ROHHAD and raise awareness.

**How long will the study last and where is it happening?**

This study will last for 13 months from November 2024 and will be taking place across the United Kingdom and the Republic of Ireland.

**How will the information be collected and used?**

University Hospitals Bristol and Weston NHS Foundation Trust (UHBW) is the sponsor and data controller for this research study so is responsible for looking after the information and using it properly.

We will collect information about children with a new or existing diagnosis of ROHHAD from the doctors who are looking after them. Doctors will not provide names and addresses to the study team but they will provide details like sex, ethnic group and month and date of birth. They will complete questionnaires using information from medical records.

The smallest amount of personally identifiable information will be used. We cannot withdraw or remove personal information from the study as this would make the research invalid. When the study finishes, personal information will be deleted or de-personalised. UHBW will securely store information for at least 20 years.

For more details about how personal information is used in the study, please see the BPSU website.

If you want access to the information in your child’s medical records, then you should contact your child’s NHS hospital or doctor.

**What if I do not want to be involved?**

Hospitals will record if families do not want their child’s medical records to be used for audit or research. You must tell your doctor or hospital if you do not want your records to be used.

In addition, individuals living in England can register a national data opt out. Registering an opt out means that none of your child’s NHS information relating to care provided in England would be used for research or planning [www.nhs.uk/your-nhs-data-matters/](http://www.nhs.uk/your-nhs-data-matters/).

If patients have registered a National Data opt out, this will be respected, and you do not have to opt out again. Alternatively, it is possible to opt out of this study specifically, by contacting your child’s clinician**.**

**Who is funding and supporting this study?**

The British Society for Paediatric Endocrinology and Diabetes (BSPED) are funding this study. The ROHHAD association (charity) and the British Society for Paediatric Endocrinology and Diabetes (BSPED) are supportive of this study.

**Where will the results be published?**

Once the study is completed, you will be able to find the results on the BPSU website: <https://www.rcpch.ac.uk/work-we-do/british-paediatric-surveillance-unit/ROHHAD>

**Who has reviewed this study?**

The study was approved by Research Ethics Committee (24/SC/0149), Health Research Authority Confidentiality Advisory Group (England/Wales), Public Benefit and Privacy Panel (Scotland).

**Where can I go for support?**

ROHHAD association ([www.rohhadassociation.com/](https://www.rohhadassociation.com/))

**Who to contact if you have any questions or concerns?**

Dr Katherine Hawton

Principal Investigator

ROHHAD Study Team

Department of Paediatric Endocrinology and Diabetes

Bristol Royal Hospital for Children

Upper Maudlin Street

Bristol

BS2 8BJ

Email: [ROHHAD@uhbw.nhs.uk](mailto:ROHHAD@uhbw.nhs.uk)