

British Paediatric Surveillance Unit

Patient Information Sheet

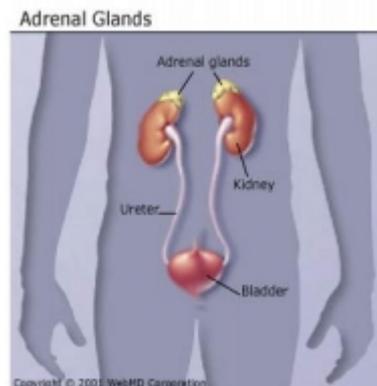
Autoimmune Addison's Disease in Children

What is Addison's disease?

Addison's disease is another name for 'adrenal insufficiency' which is a condition in which the adrenal "fight or flight" glands do not function properly to produce adrenal hormones.

The adrenal glands are attached to the kidneys and produce a number of hormones, which are chemicals that circulate in the blood and regulate the way the body works. These hormones play a role in allowing the body to cope with stress such as infections or injury and also help maintain a normal blood pressure by keeping salt in our body. Lack of these hormones can lead to major health problems, and may be life threatening, if not diagnosed and treated appropriately.

Diagram of adrenal glands in our body



Why does this condition develop?

The most common cause of adrenal insufficiency in childhood and adult life, is autoimmune Addison's disease, in which the body's own immune system attacks the adrenal glands and destroys them. Though it is now more than 150 years since the condition was first described, the disease is not always diagnosed in affected children, leading to unnecessary ill health.

How is it treated?

This condition is treated with a combination of drugs, glucocorticoids (hydrocortisone) and mineralocorticoids (fludrocortisone). These drugs will usually need to be taken for life and enable most people with Addison's disease to lead normal lives.

Patients should carry a medical identification card that states the type of medication and the proper dose in case of an emergency.

What is the study about?

This study has been designed to collect information about children under the age of 16 years with autoimmune Addison's disease. We will be asking doctors caring for a child who has been newly diagnosed with autoimmune Addison's disease to send us anonymised information. None of the information collected will identify individual children and data confidentiality will be maintained at all times.

The study will help us understand how frequently autoimmune Addison's Disease is diagnosed in children in the UK and Ireland. We would also like to find out more about the investigation and management of children with autoimmune Addison's disease as this can vary, particularly in the emergency situation.

By collecting the information about children with autoimmune Addison's disease, we hope to increase understanding of the condition and help improve care for children who are affected in the future.

Where and when is this study taking place?

The study will be taking place throughout the United Kingdom, Northern Ireland and Republic of Ireland. The researchers will be collaborating with the Addison's Disease Self Help Group (ADSHG).

The study will start in XXX and continue for 13 months.

Who should be contacted if I have any questions about this study?

Please contact the British Paediatric Surveillance Unit of the Royal College of Paediatrics and Child Health, London (see over page).

Where can I find out more about the study?

Further information about the study can be found on the BPSU website:

www.inopsu.bpsu.com.

BRITISH PAEDIATRIC SURVEILLANCE UNIT

What is the British Paediatric Surveillance Unit (BPSU)?

The BPSU encourages 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 and the Republic of Ireland are affected by a particular disease or condition each year - this is called epidemiological surveillance. Researchers can gather anonymised information about children with a particular rare condition so they can begin to understand better how to diagnose and treat children who are affected.

How does the BPSU work?

Each month the unit sends a distinctive orange card to over 2400 consultant paediatricians; this 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.

The BPSU Office informs the researchers about any reports, and the researchers send the reporting doctor a short confidential questionnaire about the child. BPSU researchers never contact families or children and a child's treatment is never affected. The purpose is ONLY to collect information to learn more about the condition.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 60 rare conditions which may affect children. These have helped to increase understanding of why these conditions occur and provided information to support better diagnosis and treatment.

(Adapted from the BPSU Public Information Leaflet – ‘Investigating rare childhood conditions for the future health of the nation’)

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