

The BSPED is one of the affiliated speciality groups of the Royal College of Paediatrics and Child Health.

The society aims to improve the care of children and young people with endocrine disorders or diabetes mellitus, by bringing together professionals from a range of disciplines.

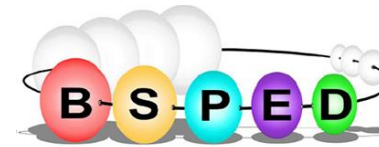
This leaflet has been written by members of the BSPED & reviewed by the Clinical Committee. It is designed to give you some general information about your child's condition and treatment. Your child's doctor or specialist nurse will be able to answer any further questions you have about your child.

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**British Society for
Paediatric Endocrinology
and Diabetes**

Diabetes Insipidus (DI) in childhood

Information for patients, parents and carers



What is a hormone?

Hormones are chemical messengers. They are made in glands and travel round the body in the bloodstream. Hormones affect how other organs in the body work.

What is the pituitary gland?

The pituitary gland is a pea-sized gland which lies deep within the brain and controls many body functions. It is made up of two parts (lobes). These are called the anterior (front) and the posterior (rear) lobes. The posterior pituitary makes a hormone, called antidiuretic hormone (ADH) (also called vasopressin). ADH controls the fluid balance in the body.

The amount of ADH secreted by the pituitary is determined by sensors in the brain. These sensors monitor the concentration of the blood and make adjustments for this. For example:

- if you are becoming dehydrated, more ADH is made. This helps reduce fluid loss in the kidneys
- if the blood is too dilute from drinking too much fluids, less ADH is made and the kidneys pass out more urine

What is diabetes insipidus?

In cranial (central) diabetes insipidus (DI) not enough ADH is made.

This leads to a lot of water loss in the urine. This causes dehydration, which leads to the child feeling thirsty and drinking more fluids.

In a small number of children the part of the brain that controls thirst is also damaged and so the child does not feel thirsty even when they are very dehydrated. If this is not recognized and the child is not given enough fluids the child may quickly become very unwell.

Why does it happen?

DI happens when the posterior pituitary gland stops making enough ADH. This can be for many reasons. Sometimes the child may have a medical condition that damages the posterior pituitary such as histiocytosis, sarcoidosis, meningitis, head injury or a tumour. It can be also associated with brain malformations that affect all the hormones in the pituitary gland.

Occasionally it may be due to genetic conditions in the family.

Sometimes we cannot find a cause and then it is called idiopathic DI.

Nephrogenic DI

DI can also happen when the kidneys are unable to respond to the ADH. This is called Nephrogenic DI. It has the same symptoms as cranial DI but giving ADH treatment does not

work. There is usually a genetic cause for this and it happens more

frequently in boys than girls. This is a different condition and is treated and managed by renal (kidney) doctors.

How does it affect the child?

A child with DI is very thirsty and passes a lot of urine. The symptoms depend on how much ADH the child can make. If they can still make some the child may just get up at night to drink and pass urine. If they can make very little they can be so thirsty they will drink from anywhere, including flower vases, taps and puddles.

When these symptoms are first noticed many parents and professionals naturally assume this is a behavioral problem and try to restrict the child's drinking. If a child has DI this would obviously be very upsetting for a child and should prompt families and professionals to consider further tests.

Usually, affected children remain well if they can drink enough, but if they become dehydrated they may become very ill. If treatment with fluids is not given the child may die.

How is it confirmed?

Testing for DI involves measuring and comparing how concentrated the child's blood and urine is.

If DI is not strongly suspected, your doctor may check blood and urine concentrations first thing in the morning. If the morning urine is

concentrated, this can often exclude diabetes insipidus, especially if there has been no fluid intake overnight. In this case the urine would usually be yellow in colour.

If DI is strongly suspected, the doctor may arrange a special test, called a water deprivation test. During this the child is not allowed to eat and drink for up to 8 hours while samples of blood and urine are taken regularly to check how concentrated they are.

This is an unpleasant and potentially dangerous test and must only be performed in a specialist centre.

If DI is confirmed then the child will need to have more tests, including an MRI scan of the pituitary, to help find the cause.

DI is different from diabetes mellitus. In diabetes mellitus the problem is with high blood sugars, which causes excessive urine output and thus thirst. This is easily tested for by measuring the sugar levels in the blood and urine.

How often does this happen?

DI is rare, only developing in about 1 in 25,000 children.

Less than 10% of DI passes from parents to children. Of the genetic causes, the overall frequency in the general population is estimated to be 3 cases per 100,000 population.

How is it treated?

The missing ADH can be easily replaced with the synthetic hormone DDAVP (Desmopressin). This may be as tablets, melts, nasal spray or injections.

The effect is usually noticed immediately as the child is less thirsty and often stops getting up at night to pass urine and drink.

DDAVP should be started at a low dose, which is adjusted over several days or weeks. Children usually need 1-3 doses each day and this is often started in hospital. Your child will need regular blood tests to help the doctors find how much your child needs. When the treatment is stable then your child will only need blood tests every few months, after any dose change or if they are unwell.

If the dose of DDAVP is not enough for your child or is missed then they will once again be very thirsty and pass more urine.

Very occasionally having a very high DDAVP dose can stop urine from being passed and increase the fluid in the body. If this happens then you should miss your child's next dose and contact your medical team for advice.

How long will this treatment be needed?

This depends on the cause but usually DI is a lifelong condition. Your clinic doctor or nurse will be able to give you more information about your child.

Are there any long-term problems?

With proper medical care and management, the symptoms of DI can be very well controlled.

Suggested sites for further information

<https://www.pituitary.org.uk>

<https://www.eurospe.org/>

www.apeg.org.au