

Fact Sheet

Diabetes Insipidus

What is Diabetes Insipidus?

Diabetes insipidus (DI) is a rare disorder that can occur as a consequence of histiocytosis involving the pituitary gland. It should not be confused with the more common diabetes mellitus, also known as sugar diabetes, which results from too much sugar in the blood. Although both disorders have similar symptoms, in every other way, including the cause and treatment, they are completely unrelated diseases. The rate of occurrence for DI is not known, because there is no organized method to count the number of affected patients.

DI is a result of damage to the pituitary gland, a small gland at the base of the brain which stores and releases a hormone called ADH (antidiuretic hormone), also known as vasopressin. This hormone normally causes the kidney to control the amount of water released as urine from the body. When the pituitary is damaged, the kidneys lose too much water resulting in increased urination and leading to increased thirst.

The connection between histiocytosis and diabetes insipidus was first reported in the late 1800s. Since then, DI has been recognized as a characteristic feature of Langerhans cell histiocytosis. It is known to also occur in other histiocytic disorders, such as Rosai-Dorfman and Juvenile Xanthogranuloma.

What are the symptoms of Diabetes Insipidus?

Symptoms of DI may include:

- » Dehydration
- » Sticky mouth or reduced tears
- » Change in appetite
- » Fatigue/sleepiness
- » Low body temperature
- » Rapid heart rate
- » Low blood pressure/shock
- » Extreme thirst and frequent urination

What is the treatment for Diabetes Insipidus?

DI that goes undiagnosed and untreated can dramatically hurt a patient's everyday life. Because of the extreme urination and thirst, activities of daily living can be greatly affected: work and school schedules are interrupted, and social events may be compromised. Sleeping through the night is often not possible and travel is difficult. Some patients have been told that they have a "compulsive drinking disorder" and must go without fluids; this, however, can be dangerous and even life-threatening. Once diagnosed and treated with synthetic vasopressin called DDAVP, symptoms quickly improve and a normal quality of life is restored.

Histiocytosis Association

The Histiocytosis Association is a global nonprofit organization dedicated to addressing the unique needs of patients and families dealing with the effects of histiocytic disorders while leading the search for a cure. It is the only organization of its kind, connecting the patient and medical communities to:

- » Grow and share knowledge of histiocytic disorders,
- » Provide critical emotional and educational support to patients and families, and
- » Identify and fund key research initiatives that will lead to a world free of histiocytic disorders.

Histiocytic disorders affect fewer than 200,000 people. It is thus considered an "orphan disease" and, as such, does not receive substantial government funding for research. The Association relies on contributions from corporations, foundations and individual donors to fund critical research, build awareness and conduct community outreach initiatives.

For more information, contact:

Histiocytosis Association
332 North Broadway | Pitman, NJ 08071 USA
Phone: +1 856-589-6606 | Fax: +1 856-589-6614
www.histio.org | info@histio.org
Federal Tax ID # 22-2827069