



Central Diabetes Insipidus & Histiocytosis

A guide for families navigating a possible diagnosis.

What is histiocytosis?

Histiocytosis is a group of rare blood disorders and cancers, that occur when there is an overproduction of a type of white blood cell called histiocytes, causing tumor formation and organ damage.

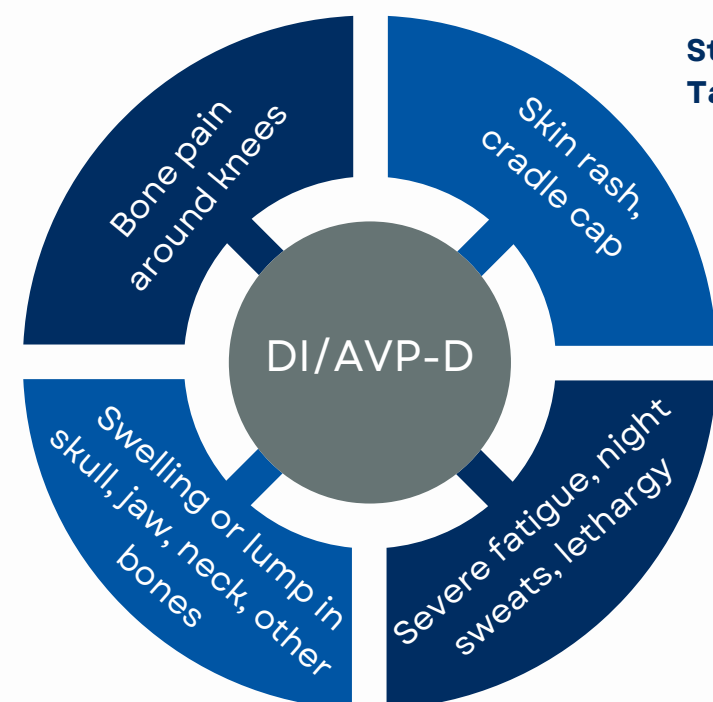
What is central diabetes insipidus (DI) or AVP-D?

Arginine Vasopressin Deficiency, AVP-D (formerly central diabetes insipidus), is a rare condition where there is 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 helps in controlling the concentration of urine in the kidneys. When the pituitary is damaged, the kidneys lose too much water (increased urination), which then leads to increased thirst.

What is the connection?

In a recent study, 10% of pituitary tumors were found to be due to the presence of a histiocytic disorder. Langerhans cell histiocytosis (LCH) and Erdheim-Chester Disease (ECD) are the histiocytic disorders known to impact the pituitary and cause diabetes insipidus.

When to think about histiocytosis if you have Diabetes Insipidus (DI) / Arginine Vasopressin Deficiency (AVP-D):



Struggling with any of these?

Talk to your doctor about testing you for histiocytosis.

Histio Resources

Visit our searchable map to find over 340 histiocytosis physicians worldwide:
www.histio.org/findadoctor

Contact us with any questions about diagnosis, treatment, finding a doctor - we provide support along the way:
info@histio.org

Join a peer support call to speak with others about their histiocytosis journey:
www.histio.org/peer-chats

