

WALK WITH WAPO THIS OCTOBER FOR PITUITARY AWARENESS MONTH AND LEARN ABOUT ARGININE VASOPRESSIN DEFICIENCY/CENTRAL DIABETES INSIPIDUS



Arginine Vasopressin (AVP) Deficiency (AVP-D), formerly known as **central diabetes insipidus**, is a rare pituitary disorder characterized by a decreased production or release of arginine vasopressin, a hormone which signals to the kidneys to retain water.

01

SYMPTOMS INCLUDE

- Extreme thirst, iced water craving
- Frequent urination
- Dry mouth, lips and skin
- Weakness
- Fatigue
- Loss of appetite
- Confusion
- Headache
- Waking up at night to drink and pass urine



"My first symptoms were very frequent and large, nearly colorless urinations and an unquenchable thirst. I urinated over 7 liters of urine in 24 hours!"

02

DIAGNOSIS IS BASED ON

- Presence of symptoms
- Blood sodium level and urine tests
- MRI imaging
- Water deprivation test
- New Copeptin-based stimulation tests



"When my daughter was diagnosed with AVP deficiency it had a major impact on the whole family."

03

MANAGEMENT AND TREATMENT

- Desmopressin (synthetic AVP)
- Symptoms such as changes in urinary frequency/volume and strong thirst must be monitored due to a risk of hyponatremia (low blood sodium)



"I quickly found out that managing it was much more complex and required monitoring on a daily basis."

04

LONG-TERM CHALLENGES

- This condition comes with invisible disabilities that need to be considered.
- Currently the only way to measure blood sodium levels is at a lab. A home blood sodium meter would make managing AVP-D easier and safer.
- Educating patients and healthcare teams about the risk of hyponatremia when taking desmopressin is still urgently needed.



"It's almost impossible to explain to someone who doesn't have my condition, which often leads to misunderstanding."



World Alliance of Pituitary Organizations

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