## Patient & Family Guide

## Central Diabetes Insipidus



## **Central Diabetes Insipidus**

#### What is central diabetes insipidus?

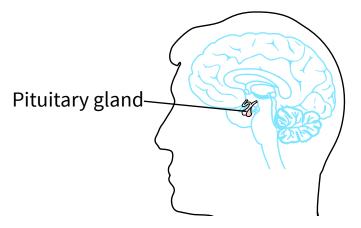
- Central diabetes insipidus (diabetes insipidus or DI) is a rare disorder of water balance.
- Usually, the amount of fluid you take in or drink will equal the amount of fluid that leaves your body when you urinate (pee).
- When you have DI, your body creates a lot of dilute (weak) urine. This causes your body to urinate more fluid than you drink. This can make you feel dry and very thirsty.

DI can easily cause dehydration (not having enough fluids). This is a serious risk for people with DI and can be dangerous. If you have DI, drink a lot of fluids so that you do not become dehydrated.

**Note:** Diabetes insipidus is not the same as diabetes mellitus. Diabetes mellitus ("sugar diabetes") causes too much sugar in the blood. DI has nothing to do with blood sugar.

#### Vasopressin (ADH)

- Your water balance is controlled by a hormone called vasopressin (also called ADH).
- This hormone is stored in and released by the pituitary gland (a small pea-sized gland at the base of your brain, just above the back of your nose).



- Vasopressin keeps your water balanced by sensing how concentrated (dilute) your body fluids are. It prevents dehydration by reabsorbing (taking back in) water from your kidneys back into your bloodstream.
- Damage to the pituitary gland can cause you to have less vasopressin. Not having enough vasopressin prevents your body from reabsorbing water from your kidneys back into your bloodstream. This causes you to urinate a lot of diluted urine and get dehydrated more easily.

#### What causes DI?

- Since vasopressin is stored in and released by the pituitary gland, any condition that damages this gland can cause DI. These include:
  - > Pituitary tumours
  - Neurosurgical surgeries (surgeries on the nervous system)
  - Radiation to the brain
  - › Head injuries
  - > Infections
  - › Bleeding in the pituitary gland
- Some people have DI only for a short time after having pituitary gland surgery, but in some cases it may be permanent.

### What are the symptoms of DI?

Symptoms of DI include:

- Too much urination of clear, diluted urine (polyuria)
- Extreme (very bad) thirst (polydipsia)
- Extreme tiredness (usually from getting up often during the night to urinate and not getting a good sleep)

### How is DI diagnosed?

You may have tests to measure the concentration of your urine and blood. These include:

- Blood test to check your sodium (sodium can increase if you are dehydrated)
- Urine test for specific gravity (to check how dilute your urine is)
- Urine and serum osmolality (to check how concentrated your urine is)
- Water deprivation test (this test may be done to confirm DI)
  - You will not be able to drink any fluids for several hours (usually for the morning).
     During this time, your blood and urine will be collected and tested.
  - You will be weighed and your urine will be measured.
  - If you urinate a lot during the test, you may be given vasopressin to check your body's response to the hormone.

#### How is DI treated?

- Before leaving the hospital, your health care team will do blood and urine tests.
- If the tests confirm that you have DI, you will be started on synthetic (man-made) vasopressin (desmopressin, also called DDAVP).
- DDAVP comes in pills, a nasal spray, or an injection. Your doctor will talk with you about what type is right for you. Your health care team will watch you closely to make sure that you take the right dose.

#### The goals of treatment with DDAVP are:

- to balance the concentration of your body fluids. This is measured by doing blood tests.
- to prevent you from having to urinate a lot during the day and at night.
- An important part of your treatment is to balance how much fluid you take in with how much you urinate. If this disorder is not treated, you could get seriously dehydrated.

### **Nova Scotia DI funding program**

- Nova Scotia residents who have DI and do not have private insurance coverage for medication may get help paying for their DDAVP through Nova Scotia Pharmacare.
- To use this service:
  - Your doctor must notify Nova Scotia
     Pharmacare in writing.
  - You must get your medication from the Metropolitan Drug Dispensary in the IWK hospital.

If you cannot balance how much fluid you take in and how much you urinate, call your primary health care provider. Signs of this imbalance include:

- Urinating a lot of clear, odourless (no smell) fluid
- > Being very thirsty

#### For more information:

# Genetic and Rare Diseases Information Center (GARD)

- https://rarediseases.info.nih.gov/ diseases/6015/central-diabetes-insipidus
- > Phone (toll-free): 1-888-205-2311
- > Phone: 301-251-4925

Notes:			

#### Looking for more health information?

Find this pamphlet and all our patient resources here: https://library.nshealth.ca/PatientEducation Contact your local public library for books, videos, magazines, and other resources.

For more information, go to http://library.novascotia.ca

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