



# Managing DI

At-home care of a child with diabetes insipidus — a parent's perspective.

Presented By

Amy Wood, director of Raymond A. Wood Foundation

Information in this presentation is anecdotal and not to be considered medical advice.



# What's the Deal with DI?

Diabetes insipidus, you puzzle me.



# DI Puzzles Me

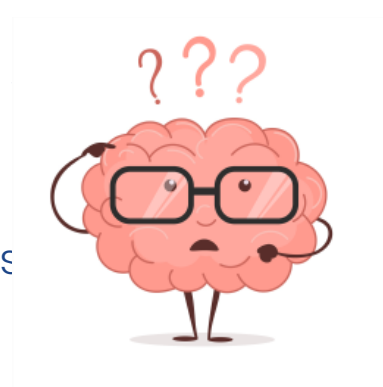
## What We Know or Don't Know About DI

Our son's pituitary gland is not releasing vasopressin. Or...maybe *doessometimes*.

Despite the same dosing schedule, DDAVP doesn't always seem to work the same day-to-day.

Breakthroughs don't always occur at the end of the dose. Sometimes they occur mid-dose.

We can't rely on him to judge his sodium. He won't ever drink water and will drink too much when it comes to sweet beverages.



# Did You Know?

## The words 'mellitus' and 'insipidus' come from the early days of diagnosing the condition.

Doctors would taste the urine to gauge sugar content.

If the urine tasted sweet, it meant that too much sugar was leaving the body in the urine and the doctor would reach a diabetes mellitus diagnosis.

However, if the urine tasted bland or neutral, it meant that water concentration was too high, and diabetes insipidus would be diagnosed. "Insipidus" comes from the word "insipid," meaning weak or tasteless.

Source: <https://www.medicalnewstoday.com/articles/183251.php>

# Did You Know?

So...we aren't going to be doing that.



# Complications of Diabetes Insipidus

## Hypernatremia

High Sodium  
Too Little Fluid



## Hyponatremia

Low Sodium  
Too Much Fluid



Seizure, Coma, Death

# The Problem

In our son, low sodium makes him more lethargic, but when his sodium is high, we can never see any symptoms.



# The Problem in Care Management

We struggle so much with her sodium .

My son has adrenal insufficiency, hypothalamic obesity, vision impairment, cognitive delays and short stature. His DI needs to be balanced with all the above.

Recently she has been diagnosed with hyponatremia. She has been hospitalized for almost 7 weeks in last 2.5 months. She needs constant sodium checks.

She can't talk so I literally have to look for signs and symptoms of too much fluid, dehydration. She can't even say "mommy, I'm thirsty."

We continue to read high most of the time because Lindsay's thirst mechanism does not work .

I take him to the hospital weekly to get his sodium checked. Sometimes 3-4 times a week. He misses school time every time we have to have it checked. Not to mention the financial burden 3-4 a week blood draws bring to our family.



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# The Problem in Care Management

- + No FDA approved home use sodium testing solution
- + Constant blood draws are traumatic for children
- + Severely high or low sodium can result in ER visits and hospital stays
- + Lag time in lab results even with STAT lab orders
- + Unreliable thirst and cognitive issues can be a side effect of brain damage making DI trickier to manage
- + The financial burden of hospital visits and lab co-pays.

# What to Do?

Start date

Aug 1 2015

12:00am

Aug 2 2015

12:00am

Apply

Time	In	Out	Net	DDAVP	Liquid	User	Actions
1:45am		-51ml	-51ml		Urine	Amy	delete
3:00am		-100ml	-100ml		Urine	Amy	delete
7:00am		-50ml	-50ml		Urine	Amy	delete
7:00am	200ml		200ml		Milk	Amy	delete
11:00am		-100ml	-100ml		Urine	Amy	delete
11:00am	100ml		100ml		Lemonade	Amy	delete
2:00pm		-150ml	-150ml		Urine	Amy	delete
5:00pm		-250ml	-250ml		Urine	Amy	delete
5:00pm	125ml		125ml		Apple Juice	Amy	delete
5:30pm	200ml		200ml		Milk	Amy	delete
7:00pm		-44ml	-44ml			Amy	delete
7:00pm		-145ml	-145ml		Urine	Amy	delete
7:45pm	236ml		236ml		Milk	Amy	delete
Total: 861		Total: -890		Total: -29			

Add Activity

**We measure ins and outs** and cross-check with sodium to get the right fluid prescription.

We give a daily amount of 1.5 liters of fluid.

# What to Do?

## **Taking morning and evening body weights without clothing**

Sudden weight changes of +/- more than a pound within 12 hours indicated too much or too little fluid on board.



# What to Do?



**Measure blood sodium levels with an i-STAT.** When things seem “off” (excessive breakthroughs or not enough urine output), we run a test.

# What to Do?

If **sodium is less than 135** we hold fluids and DDAVP until breakthrough.

If **sodium is greater than 145** we give extra fluids and keep with current DDAVP dosing.



# About the i-STAT: The Pros

## It's Pretty Accurate

Usually results are within less than 2 points of lab results

## It's Fast

Results are returned within minutes

## It's Painless (For the Most Part)

Blood is collected via a finger stick

## Reduces Lab & ER Visits

At-home management has allowed us to avoid multiple weekly lab trips



# About the i-STAT: The Cons

## It is Not FDA Approved for Home Use

Can only be purchased by a licensed medical provider

## It is Not Covered By Insurance

Since it is not an approved treatment, insurance won't cover it



## It's Expensive

The device runs around \$10K and test cartridges are \$10 each



## It Requires Routine Software Updates

These require a computer connection and some technical know-how

# About the i-STAT

## Who Benefits from an i-STAT?

Younger, diaper-bound patients that cannot articulate how they are feeling.

Patients with no thirst mechanism or an unreliable thirst mechanism.

Patients with a low tolerance of high or low sodium.

Patients with cognitive issues that make judging thirst difficult.



# How to Get One

## Abbott Laboratories Physician Guided Patient Care Program

Requires a physician's prescription and willingness to participate in training and management

**Contact:** [apoc\\_pgprg@abbott.com](mailto:apoc_pgprg@abbott.com)

## Raymond A. Wood Foundation

i-STATs are provided as long as funds are available and a physician is willing to accept it as part of care management is required.

**Contact:** [rawoodfoundation.org](http://rawoodfoundation.org)

# How Can We Make i-STATs Available?

- ✓ We are making health insurance companies aware of this device and its value in managing this condition
- ✓ We are making physicians more aware of the accuracy of this device in measuring serum sodium
- ✓ We have served as a “watchful eye” over the APOC program
- ✓ We continue to work to raise funds to provide these devices on a first-come, first-served basis

# The Good News

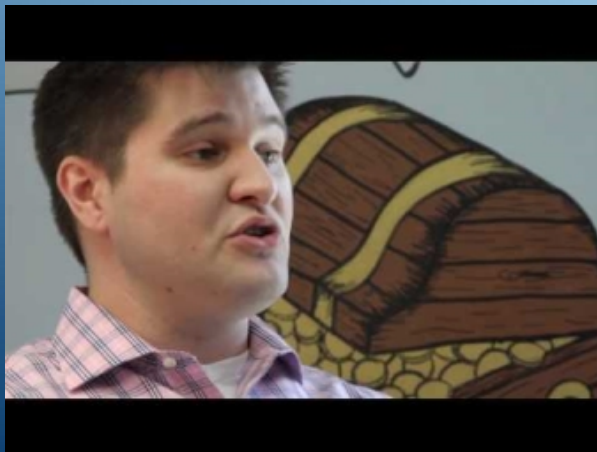
There is hope in better managing challenging DI.

Daily body weight and measuring ins and outs are helpful tools in gauging fluid balance.

There is a device that can test sodium outside of lab and it is becoming more available.

We don't have to "take a sip" to know if our kids have high or low sodium.





**Thank You!**  
For more information, visit  
**[rawoodfoundation.org](http://rawoodfoundation.org)**