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TROPICAL LIFE

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Posted on Tue, Jun. 14, 2005

ON THE HEALTH FRONT

Diabetic children will lobby in D.C. for more research

BY DESONTA HOLDER
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For most of his life, Zachary Ullman, 17, has lived with juvenile diabetes. He was diagnosed at 15 months old when he almost went into a diabetic coma.

When his first-grade class was treated to cup cakes, an insensitive teacher told him, "You'll die if you eat it." He ate one anyway, and when he checked his blood sugar he realized he could have eaten two.

Two years ago, his teacher thought his insulin pump was a cellphone and told him to give it to her. And he remembers an assistant principal ripping away a friend's insulin pump because she thought it was a beeper.

If your blood sugar goes "really low or high, you might not make it, and if you start convulsing and pass out, an A.P. [assistant principal] might assume you're drunk," Zachary says.

The Boca Raton teen, along with 7-year-old Sebastian Vassas-Cayón in Miami, have endured plenty with the disease, which causes the pancreas to produce little or no insulin. They are among 150 children in the United States -- six from Florida -- with juvenile diabetes who will attend Children's Congress in Washington, D.C., June 18-22. Along with actress Mary Tyler Moore, chairman of Juvenile Diabetes Research Foundation International, they will push for more research and a cure. Some of them will testify at

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a hearing before the Senate Committee on Government Affairs.

Sebastian was diagnosed when he was 3. He was extremely thirsty, reaching for any glass or cup that he could get his hands on, says his mom, Maggie Cayón. "I would pour the milk and he" practically slurped it. "I thought it was strange."

During a doctor's visit, a blood test confirmed he was dehydrated. "I kept on screaming and crying," when they tried to insert an IV, Sebastian says. He ended up spending a week in the hospital.

His message to Congress: "Find a cure."

Cayón, a JDRF board member of the South Florida Chapter, would like to see the Bush administration expand stem-cell research. "I don't think it should have become a political issue or a religious issue," she says.

One facet of stem cell research involves using human embryos to get embryonic stem cells. Scientists would use them in hopes of replacing tissue to treat diabetes and other diseases. In the process, embryos would be destroyed. The issue has become controversial as some politicians say they believe life begins at conception, thus destroying an embryo is akin to destroying a life.

MILLIONS AFFECTED

About 1.3 million Americans have juvenile diabetes, also called Type 1 diabetes. Globally, about 4.9 million people have the disease, which prevents people from getting energy from food. It strikes suddenly, leaving the patient dependent on insulin daily for survival. JDRF is focused on stem cells as well as other research including perfecting islet transplantation, which involves removing the insulin-producing cells from a donor's pancreas and transferring them to a diabetes patient. In the next five years, JDRF plans to contribute \$1 billion to research.

Zachary wants Congress to know the scope of juvenile diabetes. In his application for Children's Congress, he wrote:

Whenever I drive, I have to ensure that my blood sugar is in its perfect range or risk causing an accident from symptoms similar to driving drunk. . . When storms are predicted, I have to secure and refrigerate emergency supplies for an extended period of time, and with the amount of hurricanes hitting Florida, securing these supplies becomes more and more difficult after each storm. . . No one should have to endure seizures when they are asleep due to a low blood sugar and no one should have to die from "dead in bed syndrome," caused by undetected low blood sugar at night.

"Because I've not had serious problems doesn't mean others haven't had serious problems," Zachary says. "You can die. You can have kidney and heart problems if you're a teen at ideal weight."

He thinks he might be developing kidney disease, but won't know for sure until he undergoes tests.

Both he and Sebastian have had thousands of insulin shots and thousands of finger pricks to test their blood sugar.

"It's gotten to a point where there's no pain; it's routine," Zachary says. "Jabbing yourself should not be routine if you're healthy."

Zachary now wears an insulin pump to help control his blood sugar. But there are still some nights when "I wake up in a cold sweat, shaking and barely able to walk. . . I worry about my blood sugar. . . If my blood sugar drops, it could jeopardize what I do."

EMERGENCY KIT

Cayón has heard horror stories about a child's blood sugar falling so low that he or she starts to have convulsions. That's why she keeps an emergency kit with a prefilled syringe. So far, she hasn't had to use it. She also keeps a device similar to a baby monitor in Sebastian's room. And at Sunset Elementary, where

a good level for karate class at Star Gymnastics in Boca Raton. Here, he works with Jaime Caudle, 7, on Tae Kwon Do.

Sebastian just completed the first grade, the school nurse keeps an eye on him.

Next year, Zachary will graduate from Atlantic High School's International Baccalaureate program in Delray Beach. He's considering a career in law or politics after college at either the University of Florida or Florida State University. While some high school students worry about being accepted at the college of their choice, Zachary has other worries.

"I have to worry about health insurance from Day 1 and how to get my medication in college," he says.

He wants the United States to be more aggressive in the battle against diabetes.

"The U.S. should be the leader in finding a cure," Zachary says. "It would enhance our image. . . It's hard to get diabetes medication in some parts of the world. A cure would help a lot of people."



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