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Dealing with Diabetes

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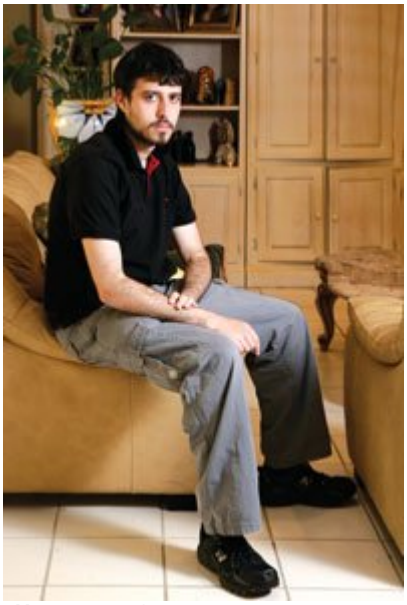

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Zachary Ullman was born in autumn 1987 with an insatiable thirst that kept parents Ellen and Jeffry in, what seemed like, constant diaper-changing mode.

On the one hand, the first-time parents were happy that their son had a healthy appetite. However, as the wet diaper count remained unusually high, the Ullmans began to wonder if healthy was the right word to describe Zack's condition. They asked their pediatrician if Zack should be tested for diabetes, which has warning signs that include their son's symptoms. The doctor said that "drinking a lot and peeing a lot was an old wives' tale" as far as detecting the disease.

A few months later, in February 1989, the Ullmans were frantically rushing their son to the emergency room at Miami Children's Hospital. Zack, only 15 months old, labored to take a simple breath. He was vomiting, and he was weakening by the minute.

An ER nurse sliced the child's finger with a razor-sharp lancet to draw blood and quickly test his glucose level. It was off the charts. His little body, unable to produce enough insulin, was burning fat as a fuel source, resulting in life-threatening levels of organic acids in the bloodstream and heightened blood sugar. Zack was in the throes of diabetic ketoacidosis (DKA).

Doctors confirmed what the Ullmans had suspected all along. Their son was a type 1 diabetic. The lives of Ellen, Jeffry and Zack never would be the same.

"Most people, even doctors, don't [understand] the psychological toll diabetes can have on a family," says Ellen, who lives with her husband in Boca Raton. "Our whole world [became] consumed with what to do next—when to test Zack's blood, when and what to feed him, and how often to check him at night."

Most people, even doctors, don't [understand] the psychological toll that diabetes can have on a family."
—Ellen Ullman, Zack's mom

Today, Zack, 21, is a junior at the University of Florida, majoring in political science. Over the years, he's learned to live with daily insulin injections and, later, an insulin pump. As many as 10 times a day, he'll prick his finger and test his blood-glucose level. He has quarterly checkups to evaluate blood-glucose levels and insulin doses; doctors also test for nerve disorders, diseases of

the kidney and thyroid, and celiac disease (which involves an inability to tolerate gluten)—all conditions to which diabetics are particularly susceptible.

The impact that diabetes continues to have on Zack and his parents has been life-altering in more ways than one. However, the Ullmans are hardly alone.

Over the last 15 years, the number of people with diabetes in the United States has doubled, making it our nation's fastest-growing chronic condition. More than 24 million people live with the disease, according to reports released last year by the Centers for Disease Control and Prevention (CDC). That's nearly 8 percent of the national population. In Palm Beach County, 9 percent of the population has diabetes.

If those numbers seem startling, then the forecast is nothing short of mind-numbing. The CDC estimates that another 57 million Americans have prediabetes—blood-glucose levels higher than normal but not elevated enough to be called diabetes—and most of them don't know it. According to the American Diabetes Association (ADA), many of those people will become type 2 diabetics within 10 years. In fact, if the trends continue, the ADA predicts that one in three Americans eventually will have diabetes, reducing his or her life expectancy by 10–15 years.

The good news is that there is hope—much of it originating here in Florida—in the form of research, advanced techniques for diagnosis and treatment, and professional and private advocates committed to stopping the disease in its tracks.
However, as residents in and around Boca can attest, the challenges grow more daunting by the day.

What is diabetes?

People with diabetes have either a pancreas that produces no insulin (or insufficient amounts) or a system that doesn't effectively process insulin. Insulin is a vital hormone that allows sugar (glucose) to penetrate cells and convert into energy.

There are two main types of diabetes:

Type 1 diabetes is an autoimmune, genetic or environmental disease that cannot be prevented. The body, in this case, produces no insulin. It most often strikes children and young adults.

Type 2 diabetes, which accounts for nine out of 10 cases, is often linked to obesity, physical inactivity, old age, problematic glucose metabolism, ethnicity and race (Native Americans and

Native Alaskans have the highest rates). Type 2 diabetics do not produce enough insulin or their cells ignore the insulin.

The price of diabetes

Sugar and fats in people with uncontrolled diabetes stay in the bloodstream and can eventually damage vital organs, increasing the risk for heart attack, stroke, kidney disease, blindness, nerve damage and amputation. Since 1987, the number of deaths related to diabetes has increased by 45 percent; over that same period, the fatality percentages connected to cancer, heart disease and stroke have decreased.

The economic impact of those living with diabetes, meanwhile, is nothing short of staggering. One out of every $5 spent on health care goes toward caring for people with the disease. In 2007, according to the ADA, the overall cost of diabetes in the United States reached $174 billion—more than 30 percent higher than the cost in 2002.

Susan and Rick Tamminga know all about the out-of-pocket toll exacted by diabetes. Two of their children, Ellie and Reed, were diagnosed with type 1 diabetes at age 9; their third child, Ryan, 7, is currently undergoing testing for the disease. Last year, the family moved to Weston from Chicago because they couldn't afford the medical costs associated with the chronic illness.

"For both children, the insulin cost was $900 a month; the doctors visits were $350 for each child," Susan says. "I couldn't work outside the home because the school Ellie attended didn't have a nurse, and the teachers weren't comfortable testing blood or administering insulin. They'd send her by herself to the bathroom when she'd say her blood sugar was high—and then they'd find her on the bathroom floor.

"Being self-employed in Chicago, our private insurance cost more than $1,000 a month—and covered almost nothing. My husband accepted a job in Florida [with Baker Concrete Construction] so that we could have health insurance supplied by an employer."

Today, both Ellie, 15, and Reed, 12, have insulin pumps that were donated by an organization in Chicago. The device gives them automatic insulin injections throughout the day, but they still must test their blood, adjust the insulin in their pumps and watch their diets.

"Going back to school after I found out about the diabetes was really hard," says Ellie, who enjoys cheerleading, surfing, track and drama. "When other kids would see me testing my blood, they'd sort of freak out because they thought there must be something really weird and wrong with me. I can talk freely about it now, and I tell people not to call kids with diabetes names. We're just trying to take care of our bodies so that we can keep doing the things we love."

One of those passions involves giving back to others with diabetes—a family project that includes Ellie's 92-year-old great-grandmother, whose husband had diabetes.

"When I was rushed to the hospital [at age 9] for what I thought was the flu, the staff at the hospital let me pick out a handmade blanket," Ellie says. "The shots were scary, and the blanket was like a piece of heaven to me. Now, my whole family makes blankets for other children so they won't have to be scared when they find out [that they have] diabetes."

"We will find a cure [for diabetes]. This is not a prediction, it is a promise."
—Dr. Camillo Ricordi, scientific director of the Diabetic Research Institute in Miami

Day-to-Day Realities

People like Zack Ullman, who “doesn’t know what life is like without diabetes,” all have stories about living with the disease, from unexpected blood-sugar spikes to equipment malfunctions to uncomfortable social situations. When Zack was in first grade, he recalls one of his classmates bringing in cupcakes for a birthday celebration.

“The substitute teacher told me that I would die if I ate one,” says Zack, who plans to attend law school after graduating from UF. “Imagine how hearing that made me feel in front of the other kids. Growing up, my teachers didn’t seem to know how to handle [his diabetes]. But I never let it get in my way.”

Zack has been outfitted with an insulin pump for the past 15 years (the battery-driven device automatically delivers target-doses of insulin). He also wears a continuous glucose monitor, the Navigator, which automatically tests blood every few minutes and sets off an alarm if blood sugar is too high or low. Zack admits that he isn’t as diligent as he should be about his diet (he has a particular weakness for Pop Tarts before heading to class), but, with a few exceptions, he has lived an incident-free college life when it comes to his diabetes.

Still, he’s well aware that his condition can change in a matter of seconds.

“When I was at college freshman orientation, I broke out into a profuse cold sweat,” Zack says. “My sugar was too low, and I didn’t have glucose with me. I can’t imagine what all the other kids

must have thought when I frantically searched for a Pepsi and guzzled it. If I hadn't gotten that drink, who knows what would have happened?"

When Alexis Weisman of Davie was a child, her mother, Janet, would read to her about diabetes to help Alexis understand the condition with which she had been diagnosed at 19 months old. When Janet had to administer a shot or prick her daughter's finger, she would give Alexis stickers as rewards.
Though Alexis knew far more than most children her age about diabetes, kids still will be kids.

"I remember being at a carnival when I was about 6 and seeing my brother eating cotton candy," Alexis says. "It looked fun and delicious, so I grabbed some and ate it—my blood sugar spiked. I'll never forget my mom. She runs and grabs a stack of paper towels and covers the top of a garbage can so we would have a clean place to put my supplies and give me a shot of insulin."

Alexis, now 16, checks her blood-glucose level in the middle of the night, before meals, and before and after exercising. She even text-messages her mom with the results after checking it before lunch at Western High School. Every three days, Alexis must change the infusion set of her insulin pump to avoid infection.

Last summer, for the first time, Alexis attended a sleep-away summer camp that wasn't designed for children with diabetes. "There was only one nurse at the camp, and I was the only one with diabetes—so I pretty much had the responsibility of caring for myself. If my friends wanted to play basketball, for example, I'd first test my blood sugar to see if I needed to drink some juice before playing."

The day-to-day inconveniences of living with diabetes have done nothing to diminish Alexis' drive and dreams. She's currently ranked second, academically, in her high school class; she plays on the tennis team; and she has set her sights on an Ivy League education to study psychology and foreign languages. "I'm learning Spanish, and I want to learn Italian, French, Hebrew and Russian," Alexis says. "I want to join the Peace Corps and help others."

Lifestyle and Prevention

In 2007, more than 1.5 million new cases of type 2 diabetes were reported in people 20 and older. Unlike those born with the disease, many of those who develop diabetes later in life are their own worst enemies due to poor nutrition and exercise habits. Recent studies confirm that a healthy lifestyle not only can help prevent type 2 diabetes, it can help prevent life-threatening complications in people with type 1 diabetes. The ADA points to several areas where diabetics can make a difference in their own lives.

• Blood sugar: People with either type of diabetes can cut their risk of eye, kidney and nerve disease by 40 percent by diligently observing their blood-sugar levels.
• Blood pressure: Maintaining normal blood pressure levels can reduce the risk of heart disease and stroke by up to 50 percent.
• Cholesterol: The risk of heart-related complications is lowered by up to 50 percent in diabetics who maintain good cholesterol levels.
• Vision: Treating diabetic eye disease early with laser therapy can prevent blindness by up to 60 percent.
• Feet: Maintaining proper foot health can cut the risk of amputation by up to 85 percent.

People at risk for type 2 diabetes can lower those odds by 60 percent by losing weight and exercising 150 minutes a week. But for those whose weight is out of control, there is hope. The Journal of the American Medical Association (JAMA) reports that bariatric surgery, such as gastric banding, can help people with type 2 diabetes go into long-term remission.

Patients undergoing gastric banding have a band placed around their stomachs to reduce appetite and food intake. Surgeons at Cleveland Clinic in Weston have performed this procedure on at least 5,000 South Florida patients with type 2 diabetes.

“The performance of weight-loss procedures on obese patients with type 2 diabetes will result in remission of diabetes in up to 84 percent of cases,” says Dr. Raul Rosenthal, head of the Bariatric and Metabolic Surgery Program at Cleveland Clinic.

Making a Difference

Two decades ago, when the Ullmans learned that their son had diabetes, they made the conscious decision to help not only Zack but anyone dealing with the disease.

“I immediately asked for information on support groups so I could talk with other parents,” Ellen Ullman says. “I was amazed when Barbara Singer—one of the founders of the Diabetic Research Institute [DRI]—called. We learned that the DRI was uniquely dedicated to research for a cure; Jeffry and I knew it was an organization we needed to support.”

Ellen became a passionate advocate for DRI, as well as for insulin-pump therapy for children with diabetes. She also went back to school and will soon graduate with a master’s degree in social work from Florida Atlantic University. Ellen plans to use her degree to help families dealing with diabetes.

Jeffry, a 25-year veteran of IBM in Boca Raton, has been just as busy spearheading the company’s fundraising efforts pertaining to diabetes research. Through IBM’s charitable contributions campaign, IBM employees have donated more than $350,000 to the DRI—not to mention the donation of thousands of dollars in computer equipment through IBM’s national community grants program.

“We will not stop until a cure is found,” Jeffry says.

Scientists, including those at the DRI at the University of Miami Miller School of Medicine, have a similar mantra, and the talk is far from idle.

“The recent progress of our research toward a cure for diabetes has been remarkable,” says Dr. Camillo Ricordi, scientific director and chief academic officer of the DRI in Miami. “We are now entering a new phase of pilot clinical trials, from novel strategies for the transplantation of insulin-producing cells to injections of stem cells to promote regeneration of insulin-producing cells in the pancreas of patients with diabetes.”

Ricordi says that side effects and risks remain involving these types of cellular therapies, but once those hurdles are overcome, “every patient with diabetes will desire a cell transplant.” To

that end, Ricordi says that it's imperative to develop unlimited sources of insulin-producing cells. "That is why we are concentrating much of our efforts at the DRI on stem-cell research," he says. "We will find a cure, and this is not a prediction, it is a promise!"

Web Resources

Florida Diabetes Prevention & Control Program: floridadiabetes.org

American Diabetes Association: diabetes.org

Centers for Disease Control and Prevention: cdc.gov

National Diabetes Information Clearinghouse: diabetes.niddk.nih.gov

Diabetes Research Institute at the University of Miami Miller School of Medicine: diabetesresearch.org

Children with Diabetes: childrenwithdiabetes.com

Juvenile Diabetes Research Foundation International: jdrf.org

Cleveland Clinic's Bariatric Institute: clevelandclinicflorida.org