Destructive disease

Early to rise, Zachary Ullman, 12, performs his usual 6:15 a.m. blood sugar test. Both this test and the 4 a.m. test that precedes it, recorded higher than normal blood sugar levels. (Patti Parker / Boca Raton News)

Boca boy battles to stay one step ahead of diabetes

By Kate McClare
Staff Writer

Zachary Ullman was just a baby when he was diagnosed with diabetes. At 15 months, he was too young to understand why his mother kept hurting him with needles.

"I had to hold him down under the table (for his insulin shots)," recalls his mother, Ellen Ullman. "He’d run away."

Zachary is 12 now, and long ago stopped resisting the insulin shots that keep him alive. He manages his illness himself, checking his own blood-sugar levels and adjusting his insulin dosage as he needs. For him and his parents and younger sister, who live in west Boca Raton, management of diabetes has become a seamless part of the day’s routine.

For his parents, especially his mother, part of
the routine is the search for a cure for the illness suffered by about 18 million people. They may have accepted the chores of the disease, but they have not accepted the disease itself.

Ellen and Jeffry Ullman work closely with the University of Miami’s Diabetes Research Institute, to educate people about diabetes and support the institute’s efforts to find a cure. Ellen spends much of her day on the Internet, maintaining a Web site devoted to informing and uniting families of children with diabetes.

The message she most wants heard is that diabetes is a life-threatening illness, not an inconvenience that can be overcome by taking insulin and avoiding sweets. According to the Diabetes Research Institute, it is the leading cause of blindness in adults ages 20-74. It can lead to many other life-threatening complications, including kidney failure and heart disease. Insulin does not stop the disease’s steady attack on the body’s organs.

"I’m trying to spread the word that diabetes is a destructive disease," Ellen says. "It’s destroying my son’s body, and it can only be cured with funding (of research projects)."

Diabetes comes in two types. Almost 1 million people have Type 1, which used to be known as juvenile diabetes, because it is most often diagnosed in children. It develops because the pancreas becomes unable to produce insulin, the substance that feeds the body’s cells by converting food into glucose. Those who have it must inject themselves with insulin in order to stay alive.

About 17 million people have Type 2 diabetes, which generally occurs after age 40. Their bodies do produce insulin, but ineffectively or in insufficient quantities. Patients can take medication, but often the disease can be overcome with improved diet, exercise and other lifestyle factors.

Zachary has Type 1 diabetes, and always will until a cure is found.
His days begin and end with blood-sugar checks and insulin injections. One recent morning, he got up at 4:20 a.m. to use the bathroom, so he had to check his sugar level.

Management of his illness is a little easier now that he uses an insulin-injection pump instead of syringes. The pump simulates the workings of a real pancreas, delivering insulin through a catheter in his side. It’s a steadier, more reliable delivery system than a syringe, and it’s easier for him to use as well.

But Zachary still must check his sugar levels, keep track of how many carbohydrates he ingests, and then figure out how much additional insulin his body needs in order to convert the carbohydrates into energy.

"Yes, I am very good at math, in case you were going to ask the question," he says in his family’s kitchen at about 6:45 a.m., as he bustles about to prepare his breakfast: a cup of Kix cereal, a cup of Captain Crunch cereal, one packet of Instant Oatmeal, a cup of milk and a packet of instant hot chocolate. He adds the carbohydrates (116.75 grams), divides that by one insulin unit per 11 grams of carbohydrate, and dials the pump to give him 10.5 units of insulin. He gets one unit per 20 grams at lunch, and one unit per 24 grams at dinner.

He’s been on the pump since second grade. "Before, I had to eat healthy things all day," he says. Now he can handle more sweets because the pump makes it easier to work those foods into his diet. He isn’t usually tempted to over-indulge in sweets, however; he’s been a vegetarian since second grade.

The pump, he says, is "easier but a little annoying, because I have to change the site (of the catheter) a few times a week. The low-battery alarm will go off in school, and I have to take it off during gym class. No pockets in my shorts," he explains.

"But I can have a little more freedom in my life," he adds. "In school, if I had high sugar and needed a shot, I’d probably have to walk
down to the office." With the pump, he can quietly dial up a little more insulin.

Zachary’s illness seems little noticed at Carver Middle School in Delray Beach, where he attends sixth grade. "He might say he needs to use the bathroom right away, but mostly he just does what he needs to do and takes care of it himself," says Zachary’s science teacher, Laura Viergutz.

She admits she was apprehensive at the beginning of the year, when she first learned she’d have a child with diabetes in her class. "But his mother had a conference with all of his teachers, and she told us what to expect and that he can handle this himself." Ellen Ullman supplies his teachers with pieces of hard candy, in case his blood sugar drops.

Ellen Ullman has always started Zachary’s school year that way, and Zachary says it hasn’t always been easy. "My mom sometimes has to fight with some of my teachers against rules like going to the clinic for insulin. Like if a kid is having a diabetic episode he’s going to have time to walk to the clinic."

Zachary’s parents are hopeful that one day, children won’t have to choose between needles and pumps, because their diabetes will have been cured. Ellen figures her son has had more than 18,000 blood-sugar tests in his short lifetime, and she would be happy if he never had another one.

"A lot of organizations are focused on treatment," Jeffry Ullman says, "but we’d rather cure it than just treat it for the next 20 years."