



victimized by it as I did.” Alexa’s mom started to learn about the organizations that existed and soon began working with the Juvenile Diabetes Research Foundation (JDRF) for which she now serves on the board of directors.

Many people confuse type 1 diabetes with type 2. Children or adults with type 1 have an autoimmune disorder that destroys the pancreatic cells that release insulin. Without insulin, cells cannot absorb sugar which they need to produce energy. There is no cure and it cannot be prevented. Type 2 accounts for more than 90 percent of cases and can develop at any age, but is most common during adulthood. In contrast to type 1, insulin resistance is the main characteristic of type 2. The cells in the pancreas still function, but release insulin at a slower rate. Type 2 can often be controlled with diet and exercise.

“It’s very frustrating when people tell us that we can fix Alexa’s condition if we just do something different,” says her mother. “Type 1 requires diligence around the clock. Stress, activity, illness, hot and cold temperatures, and hormones can all affect blood sugars. While Alexa looks perfectly healthy, others cannot see what is required of her for daily management and the damage this is doing to her body.”

During her early years at a public elementary school, Alexa was not receiving the personal care she required during the day. Her family had to be certain that faculty would take her health seriously, so they enrolled her at Annie Wright at the start of her second grade year. School nurse Jan Lind and Alexa’s teachers were able to provide more individual attention and ensure that she was tested and closely monitored throughout the day.

Alexa now carries a test kit and checks her own blood about ten times per day. At night when she is asleep, her father checks her before he goes to bed, and her mother awakens at two o’clock in the morning to check her. This routine makes it very difficult for Alexa to participate in sleepovers with her friends. Likewise, her parents have never traveled without her.

Her mother says there is no one she feels comfortable leaving Alexa with for an extended period of time. “We have a big joke in the family... like, what are you going to do when Alexa goes to college?” She laughs, “I say that I am going with her!”

Her mother’s involvement in the JDRF has provided opportunities for Alexa to turn her innate enthusiasm into action. At age six, she began a campaign called “Alexa’s Athletes” to encourage friends and family to support her in the annual JDRF Walk for a Cure event. That first year, she raised \$2,000 and led a small team of supporters on the walk. Her team has since grown along with her fundraising each year. In 2007, Alexa set an ambitious goal to raise \$10,000. From the JDRF Web site, she added a link to her team page where people could donate online. She wrote letters to her father’s business colleagues and everyone else she thought would support her. At school she sold paper pin-ups of athletic shoes for one dollar each. The donations came in and she exceeded her goal by \$315.

by Lynn Enebrad

Ask Alexa Brenner about her favorite novel of all time, or which teacher she prefers, and you won’t get a direct answer. As she puts it, “All books are special in their own way, kind of like people, so I don’t pick favorites.” But you’ll also recognize several constants with Alexa – her brilliant smile, wild coils of chestnut hair, buoyant gait, and a red wristband with the words: Insulin is not a cure.

On the outside Alexa is a spunky, self-assured eleven-year-old. She looks forward to weekends when she can be in the kitchen cooking up new recipes with her dad or out shopping with her mom. But on the inside she is in a state of endless vigilance. Her hectic schedule is not easy and she manages well despite the burden of frequent interruptions throughout the day. Alexa refers to it as the “pause button on life” – the time-out she takes almost hourly to test her blood sugar level.

Alexa was just 14 months old when she was diagnosed with type 1 diabetes. The average age of diagnosis is 11 to 13 years of age. Doctors initially misdiagnosed her because they did not believe she could have the disease at such a young age. When Alexa began slipping into a coma, she was rushed to Mary Bridge Children’s Hospital where she spent a week in intensive care. “We were devastated,” says her mother Georgia Spiropoulos. “When we brought her home we realized it was just the beginning of a long road that we knew nothing about. We were so overwhelmed!”

It took Alexa’s parents a long time to come to terms with their daughter’s diabetes. By the time Alexa was four, her mother finally realized that how she handled the disease would teach Alexa how to handle it through her own lifetime. “I wanted Alexa to be a part of the solution, the cure, and not feel

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Alexa also wrote an essay to Congressman Norm Dicks expressing how living with diabetes affects her, why finding a cure is important, and why she should represent Washington State at JDRF Children's Congress 2007. A month later an envelope arrived announcing she had been selected as a delegate. Alexa was overjoyed!

All 150 national youth delegates traveled to Washington D.C. in June to address a panel of lawmakers in the Congressional Hall on a day when the temperature was over 100 degrees. Heat quickly raises the blood sugar of people with diabetes, and although the room was air-conditioned, most of the young delegates seated before the panel were constantly testing their blood as they lobbied for funding. The scene made quite an impression. Alexa recalls, "Seeing 150 kids with the same condition was shocking!"

While in D.C., Alexa spoke with Washington State Senators Patty Murray and Maria Cantwell. "When meeting with lawmakers, I really push the point that insulin is not a cure. Simply controlling diabetes is not curing diabetes," says Alexa. "A common assumption is that if one can live with the disease then it is not necessary to find a cure. Twenty-five percent of the money that goes to type 1 research is funded by people like me. Other disease research foundations don't receive even close to that percentage from individuals." Senator Murray sympathized with Alexa's plight and pledged her continuous support, however, she expressed that government funds for research were becoming very difficult to obtain.

That disappointment hasn't stopped Alexa from trying. She has already raised over \$40,000 for diabetes research. She acts as a youth leader at Mary Bridge where she talks with young girls newly diagnosed with diabetes, and provides a brave face of hope through her crusade for a cure. Alexa's commitment is inspiring when she speaks on the importance of science education for the future of medical research. She encourages others to pursue



Above: Alexa Brenner presents her case for funding to Senator Maria Cantwell at the JDRF Children's Congress 2007



Left: Alexa Brenner with her mother Georgia Spiropoulos and Senator Patty Murray

careers in medicine or science – industries now struggling to attract newcomers. She hopes to one day become a pediatric endocrinologist so that she can better support children living with diabetes. "None of my doctors have type 1 diabetes and even though they pretend to understand, they cannot know what it's really like living with this disease," she explains. "They do not truly understand the challenges my family and I face every day."

Alexa remains optimistic, however, that research will find a cure in her lifetime. She is inspired by the hope to one day live a life free of test strips, insulin, and chronic worry. "We just can't let the money for research run out," she demands. "I'll bang down everyone's door if I have to...I'll never give up!"

Donations to Alexa's Athletes can be made at walk.jdrf.org. At the bottom of the Web page (under Support a Walker) type Alexa Brenner's first and last name to access her team page.

Knowing the warning signs for type 1 diabetes (juvenile diabetes) could save a child's life.

Warning signs of type 1 diabetes (these may occur suddenly):

- Extreme thirst
- Frequent urination
- Sudden vision changes
- Sugar in urine
- Fruity, sweet, or wine-like odor on breath
- Increased appetite
- Sudden weight loss
- Drowsiness, lethargy
- Heavy, labored breathing
- Stupor, unconsciousness

If your child exhibits one or more of these symptoms, call a doctor immediately.

Education about the symptoms of type 1 diabetes is critical because type 1 can easily be mistaken for more common illnesses, such as the flu. JDRF has literature which lists the symptoms and treatments of type 1 diabetes and hypoglycemia (low blood sugar).

Each year, approximately 30,000 Americans are diagnosed with type 1 diabetes; over 13,000 are children.