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Chipping in for a good cause

Family holds golf fund-raiser for son

By Michelle Hillman
NEWS STAFF WRITER

WELLESLEY – Looking at Benjamin Siedman the average person would see a cute, happy, 4-year-old full of life and innocence.

A little boy who loves cows, toy tractors and visiting his grandmother’s farm in Minnesota. Someone who dreams of growing up to one day own a farm where his older brother, Noah, and younger sister, Isabelle, would help him feed the animals.

Unfortunately Ben’s dreams probably will never be realized because he has a rare disease called Sanfilippo Syndrome which affects one in every 24,000 newborns in this country.

Eventually, because Ben lacks an enzyme that breaks down strings of complex body sugars called mucopolysaccharides, he won’t be able to talk or even walk. These sugars slowly build up in the brain and cause hyperactivity, sleep disorders, mental retardation and death.

Yesterday his parents, Jennifer and Stuart Siedman, held the second annual “Birdies for Ben” golf fund-raiser to benefit The Children’s Medical Research Foundation, Inc.

Twenty-eight of the Siedmans’ closest friends, family members and co-workers spent a portion of their day at the Sandy Burr Country Club in Wayland to help Ben and children like him.

All of the proceeds from the event go to funding researchers so they may find a cure for an illness which gives its victims a life expectancy of about 10 to 15 years.

While the Siedmans know a cure may not come in Ben’s lifetime, they can’t sit back and let the illness take their son without doing anything to help.

“We had so many doctors say to us ‘there’s nothing we can do, go home,’” Jennifer said. “That wasn’t enough for us. We’re not the sit still type of people.”

The Siedmans decided to get involved with the Foundation, which was established in 1995 by Bradford and Susan Wilson, a Chicago couple who established the foundation after their daughter, Kirby, was diagnosed with Sanfilippo.

Stuart received a paid year off from his employer, the Xerox Corporation, to raise money for the fatal disease. Through the



PHOTO BY TIFFANY WHITE

Tom Hitchcock of Lexington watches play during the benefit golf tournament at Wayland’s Sandy Burr Country Club.

company’s social service program, he is able to do everything he can to help find a cure for his son and help the Foundation dedicated to raising awareness and funds for scientific and medical research.

Already researchers have successfully cloned the human gene and DNA encoding of the missing enzyme in Sanfilippo patients, allowing them the potential of correcting the gene.

Last year the Siedmans’ golf event raised over \$79,000. As of yesterday, friends and family had raised \$50,000 for the

Golf for a good cause

GOLF, From B1

Foundation. To date, the Foundation has granted more than \$1.2 million to researchers. This year, the family received help from local merchants.

The Siedmans acknowledge that Sanfilippo will someday take hold of Ben's mind and body. The only physical signs of the syndrome Ben has currently is a stiffening in his joints and a loss of his range of motion.

Right now there is no cure for the genetic disorder. But the Siedmans and others like them are helping to speed the process for finding a cure. In less than five years the number of researchers has increased from one to six.



PHOTO BY TIFFANY WHITE

Timothy Carpenter, Benjamin's uncle, watches the flight of his ball during the tournament to raise funds for research into Sanfilippo Syndrome.



PHOTO BY TIFFANY WHITE

Stuart Siedman, Benjamin's father, checks in golfers at the benefit tournament he and his wife started last year.

"You can't stop hoping," Jennifer said. "Then what are you going to do? If you stop hoping, you might as well stop being."

For now Ben is full of energy and curiosity about animals, farm life and especially tractors. He loves visiting Starbucks for a cup of milk and banana bread. He enjoys painting with his preschool classmates and playing with his brother and sister.

Neither Ben nor his brother and sister know his fate. The Siedmans appreciate every moment they have with all of their children and continue working for a cure.

"We just said 'if we don't do something, who else will?'," Stuart said. "We obviously have to do everything we can for our child. If other children are helped in the process that's even better."

Ben's Dream – The Sanfilippo Research Foundation, Inc. has applied for public 501(c)(3) non-profit status. Its mission is to raise funds to increase public awareness and support research into finding a cure for Sanfilippo Syndrome.

Donations to Ben's Dream can be made payable and sent to:

The Sanfilippo Research Foundation, Inc.

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<http://www.bensdream.org>