

# The METROWEST DAILY NEWS

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## Boy's plight rallies community support

Wellesley salon hosts a raffle to raise money for Sanfilippo Syndrome research

By Michelle Hillman  
NEWS STAFF WRITER

WELLESLEY – Benjamin Siedman might not realize why people in the community are pulling together in his name, but hopefully one day he will.

Yesterday, the Wellesley boy drew the winning names from the "Not Your Ordinary Raffle," organized by Trillium Salon in Wellesley. The raffle raised \$5,000 to be donated to finding a cure for Sanfilippo Syndrome.

"The effort here has been tremendous," Ben's mother, Jennifer, said about the community support the family has received since fund raising began 18 months ago.

Siedman, 4, has the rare disease that affects one in every 24,000 newborns in this country. Siedman's parents, Jennifer and Stuart, have not yet explained to their son what lies ahead.

For now, they want him to enjoy his newfound love of bowling and cheeseburgers and old favorites like toy tractors, farms and cows.

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. Those with the disease have a life expectancy of 10 to 15 years.

To date, the Siedmans have raised \$200,000 for the Children's Medical Research Foundation Inc. in Chicago, which is devoted to researching the rare genetic disease. All proceeds the Siedmans receive go to research.

Last summer the Siedmans held the second annual "Birdies for Ben," a golf event that raised \$95,000. In November, the Lisa James Salon in Wellesley raised \$7,000 with its "Cut to Cure."

"(The Siedmans) are incredibly positive and motivated," said Laura Frigoletto, a stylist and one of the organizers of the raffle at Trillium. "They inspire everybody around them."

Jennifer and Stuart see it another way. They



STAFF PHOTO BY MARSHALL WOLF

**Ben Siedman, 5, picks the name of a winner in yesterday's raffle at Trillium Salon in Wellesley as salon owner Gretchen Monahan, left, Jennifer Siedman, center, and stylist Laurie Frigoletto watch.**

couldn't sit by and not try to do everything in their power to save their child.

"If I didn't raise this money to help Benjamin," Jennifer said, "I would have to live with that I didn't do everything I could to help my child."

"For us, this is a lifelong activity," Stuart said. "We're going to continue working toward raising money and raising awareness."

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

Stuart Siedman received a paid year off from his employer, the Xerox Corporation, last year to raise money for the fatal disease. The Siedmans were also featured on Channel 7 last April after an episode of "ER" which featured a Sanfilippo patient.

The Support the Siedmans have received extends beyond local businesses and money, Jennifer said, commenting that people will walk up to her on the street and tell her they're thinking about her and her family.

This year, Ben's preschool teacher went to a doctor's appointment with Jennifer and Ben

during February school vacation. It's those gestures, and Ben, that give Jennifer and Stuart hope.

Right now Ben is doing remarkably well, said Jennifer, but he is starting to show physical signs of the disease such as skeletal malformations.

Stuart said his son is "blissfully unaware" of his disease and is excited for his bowling birthday party this month when he'll turn 5. Ben enjoys wearing the bowling shoes more than actual bowling, Stuart said.

The Siedmans realize a cure might not be found in their son's lifetime, but everything people do to help fund research will bring them, and other families, closer to a cure.

"Every bit that's done counts," Stuart Siedman said.

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

Donations can be made payable and sent to:

Ben's Dream  
P.O. Box 81268  
Wellesley, MA 02481-0002

<http://www.bensdream.org>