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A FAMILY'S CRUSADE

Race against time to fight killer disease

Father takes leave from work to help find cure that may save son's life

By David B. Caruso
NEWS STAFF WRITER

The tough part will come later.

Right now, 3-year-old Benjamin Siedman of Wellesley is a healthy kid. He loves flipping through picture books about farms and playing with his stuffed cow, Milkshake. He can talk to his parents. He can walk. He can feed himself.

Odds are by the time he is 10 he will have difficulty doing all those things.

And by the time he is 15 . . .

"Right now there is really nothing they can do," said his father, Stuart. "Life expectancy for a child with Sanfilippo Syndrome is only 10 to 15 years."

Born without an essential enzyme that would allow his body to break down complex sugars, Benjamin is living on borrowed time.

As the years go by, strings of sugar molecules called mucopolysaccharides will build up in his system and begin to affect his motor functions, his speech, and eventually his vital organs.

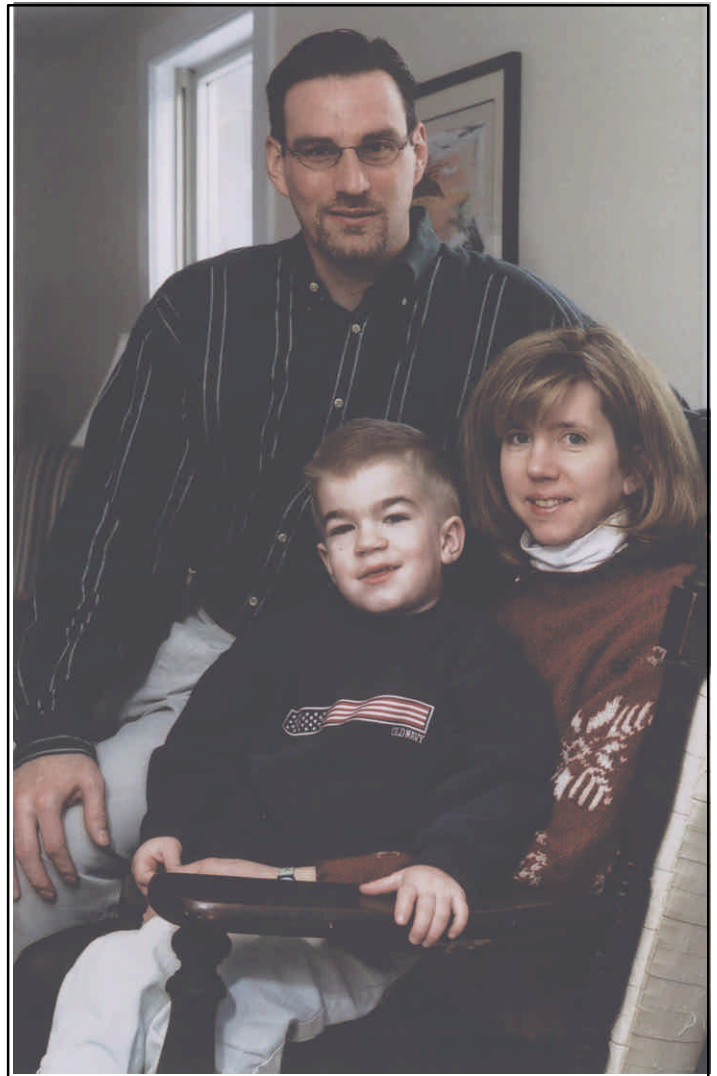
"He is basically poisoning himself to death," his mother, Jennifer, said.

Moved by the boy's plight, the Xerox Corporation recently gave Stuart Siedman a paid year off from his job as a product manager to raise money for research into the fatal disease.

Last month, Siedman began working full time for The Children's Medical Research Foundation, Inc., a volunteer fund-raising organization founded in 1995 by a Chicago couple with a daughter afflicted by Sanfilippo.

In three years, the young foundation has distributed close to \$900,000 in research grants, all without the help of a single paid staff member or professional fund-raiser.

The Siedman's found the foundation and its creators, Bradford and Susan Wilson, on the Internet 2 1/2 years ago shortly after Benjamin was diagnosed. Since then, the Wellesley family has raised nearly \$80,000 for the foundation through a golf outing at Sandy Burr Country Club in Wayland. But Siedman hopes to spend his year on leave from Xerox helping the foundation build a



STAFF PHOTO BY ART ILLMAN

Benjamin Siedman, 3, who has Sanfilippo Syndrome, is pictured here yesterday with his father, Stuart, and mother, Jennifer, at their Wellesley home.

larger network of volunteers interested in funding what little research there is into Sanfilippo Syndrome.

"This isn't something as known as cancer or AIDS. It doesn't have the profile. It doesn't get research dollars, so we have to work especially hard," he said.

Add to that the fact that Sanfilippo Syndrome is relatively rare — affecting an estimated 1 of every 24,000 newborns — and that

Race against time

CRUSADE, *From Front Page*

there are only a handful of researchers working on identifying a cure and the family's job is even tougher.

Xerox has given Siedman leave through its 28-year-old social service program, which gives from six to 18 employees a year the chance to take time off from work to concentrate on a philanthropic pursuit.

Other participants in the leave program this year include an employee in Texas raising money for a Boys & Girls Club, an Arizona employee working as a volunteer with cancer patients and a worker in Rochester, N.Y., trying to get computers to inner-city families.

Siedman's job will still be there for him when he returns, Xerox spokesman Carl Langsenkamp said.

"We have had a whole range of employees participate in this program, from line workers all the way to a vice president, and we feel they have all been able to make a real contributions to their community," Langsenkamp said.

"When they come back, they often come back with better ideas on how to serve Xerox, too, so it is a win for everyone."

For the Siedmans, the next few years may be the only time they have to devote to their cause. Once Benjamin's illness worsens, they expect to have less and less time to focus on research fund-raising.

It will take years before the 3-year-old starts to get sick, but most children with Sanfilippo Syndrome eventually lose their ability to speak, to walk, to feed themselves – even to sleep through the night.

"Benjamin is doing pretty good right now. He is pretty much a normal 3-year-old. A happy, normal kid. He knows that he goes to the doctor very frequently, but other than that there is nothing about him that would tell him he is ill," Mr. Siedman said.

Romping about the family's home yesterday, Benjamin seemed the picture of health – active, talkative, extremely intelligent.

But that will all change as the unprocessed body sugars build up in his system. Within a few years, the family expects to have a full-time job just taking care of him.

"He will probably be wheelchair-bound by the time he is 10," Mrs. Siedman said.

There is no known treatment or cure for the condition. The Siedmans have been teaching Benjamin sign language with the hope of preserving his communication skills as long as possible.

He has shown only a few symptoms to date, mostly a slight lag in speech development. The family did not suspect a serious illness at all when they brought him to the hospital 2 1/2 years ago for a high fever, and found out through a chance test that he had Sanfilippo.

Both of Benjamin's parents carry a recessive gene that can cause Sanfilippo Syndrome, but do not have the disease themselves. There is a one-in-four chance that two parents with the recessive gene will have a child so afflicted.

They have also begun preparing Benjamin's 6-year-old brother, Noah, for what probably lies ahead, though they still have not told him or his younger sister, Isabelle, that their brother is dying.

"We're explaining to Noah a little bit now. When he asks questions, we answer them. And we are trying to let him know as often as we can that some people aren't lucky," Mrs. Siedman said.

"We take him to the (Boston) Marathon, and he sees the people



STAFF PHOTO BY ART ILLMAN

Benjamin Siedman, 3, who has Sanfilippo Syndrome, is pictured here yesterday at home. Benjamin's father, Stuart, has taken a year off from work to help raise research money.

in the wheelchairs and asks why they wound up like that, and we tell him that sometimes people aren't lucky and bad things happen to them."

The family is hoping that advancements in gene therapy and medical research will help find a cure before it is too late for Benjamin, but they are realistic about his prospects.

"Sometimes it is hard to plan for the future and to look forward to the future, knowing what probably lies ahead for us," Jennifer Siedman said.

"But we really owe it to all our children to look forward to that day anyway, and to plan for it."

The Children's Medical Research Foundation, Inc. is a 501(c)(3) non-profit organization that raises funds to increase public awareness and support research into the causes of, and cures for Sanfilippo Syndrome and other neuro-genetic disorders afflicting children.

Tax deductible donations can be made payable to:

The Children's Medical Research Foundation, Inc.
Attn: Ben's Dream
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