



WHDH-TV Boston

Healthcast Reports

Reported by Kim Carrigan

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Part of tonight's episode of "ER" focused on a little girl with Sanfilippo Syndrome, a rare and fatal genetic disorder. Tonight we introduce you to a Wellesley family fighting their own battle against the deadly disease and hoping for a cure.

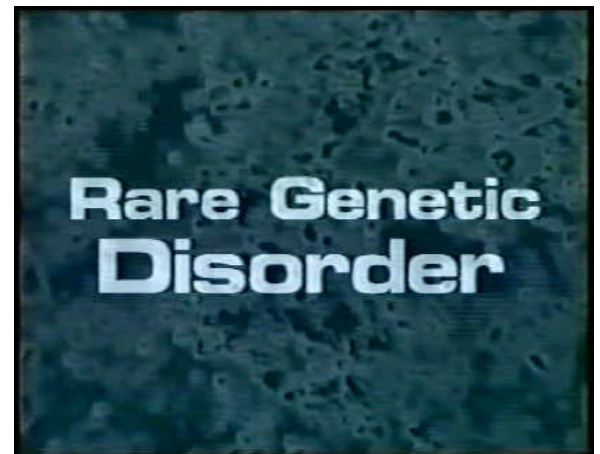
It's another day at pre-school for four-year-old Benjamin. Time to learn and be with friends. Here, he's just one of the guys. He plays, shares stories, and enjoys snack time. But in a few short years that could all change.



Stuart & Jennifer Siedman, Ben's parents

"By the age of eight he will have lost his speech totally, Age ten the child is wheelchair bound, between twelve and fourteen, their organs just stop functioning."

Benjamin has Sanfilippo Syndrome, a rare genetic disorder that affects one out of every 24,000 newborns in the US. Ben has an enzyme that doesn't break down a complex sugar in his body. Eventually it will build up in his brain, becoming toxic and possibly shortening his life by the time he reaches adolescence.



Jennifer Siedman

"Devastating isn't even a word that begins to describe all of a sudden your whole life changes."

Stuart Siedman

"It's a very tough thing to think about."

Dr. Mark Korson, Boston Children's Hospital

"Most parents are in shock."



Dr. Mark Korson says that most children aren't diagnosed until they're between the ages of 2 and 7. Symptoms can be subtle, often mimicking common developmental problems like delayed speech, Attention Deficit Hyperactivity Disorder, or ADHD, and recurring ear infections. Other signs include changes in facial features and stiffening in joints. A definitive diagnosis usually comes after a specialized urine test.

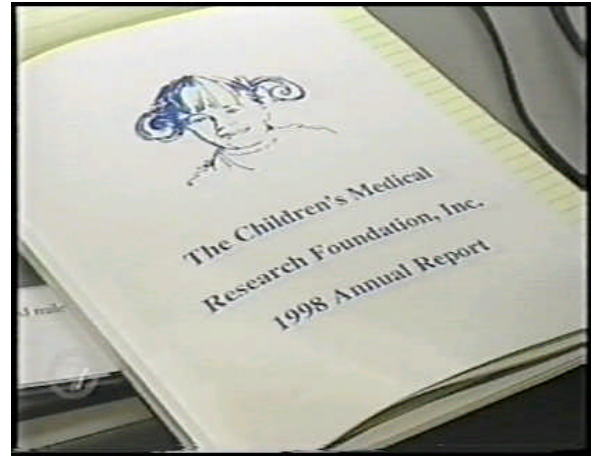
Dr. Korson

"It doesn't become clearer until later on in childhood until the child develops neurological problems, like losing their speech."

Right now, there is no cure and no treatment. Realizing it's a race against time, Ben's parents are doing all they can. Stuart Siedman's employer, Xerox, has given him a paid year off. Now he works full time for 'The Children's Medical Research Foundation', a volunteer group that raises money to fight the killer disease.

Stuart Siedman

"The more researchers that are working on this the faster and better chance there is that there will be a cure."



Right now, life is pretty normal for Ben. His parents are trying to ease the changes his body will go through by using sign language and physical therapy. But no matter how much they prepare, the Siedman's know each moment with Ben is precious.



Jennifer Siedman

"It makes you really appreciate every little thing."

Stuart Siedman

"He's a very happy child, and as long as he remains that way I'll be able to push and find something. When that changes I think that's going to be one of the toughest times, and hopefully it won't."

Researchers worldwide are working to find a cure for Sanfilippo Syndrome, but they say without the proper funds it could take years. For more information on Sanfilippo Syndrome you can contact:

The Children's Medical Research Foundation

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