

RYE BROOK Westmore NEWS

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Case #513: Rebecca's fight

Rye Brook girl has rare genetic disease

By Masha Rumer

Rebecca Newman is a typical eight-year-old girl whose favorite thing about school is recess, who laughs a lot, enjoys playing with American Girl dolls, and gets upset when her parents tell her to go to bed early on a school night when she'd rather stay up and watch TV with her sister.

What sets Rebecca apart from her peers is that she sees eight therapists—occupational, physical, and speech—per week and drinks 95% of her liquids through a feeding tube in her tummy, which her family affectionately calls “the button.”

“I can talk and drink at the same time,” Rebecca says coyly about “the button”'s positive aspect.

Rebecca was born with a rare genetic disease called Familial Dysautonomia, or FD. Like Tay Sachs, people of Ashkenazi (or Eastern European) Jewish descent are most susceptible to passing this disorder to their children. This is likely if they both carry this rare gene, and even then there is only one out of four chances their child will inherit FD.

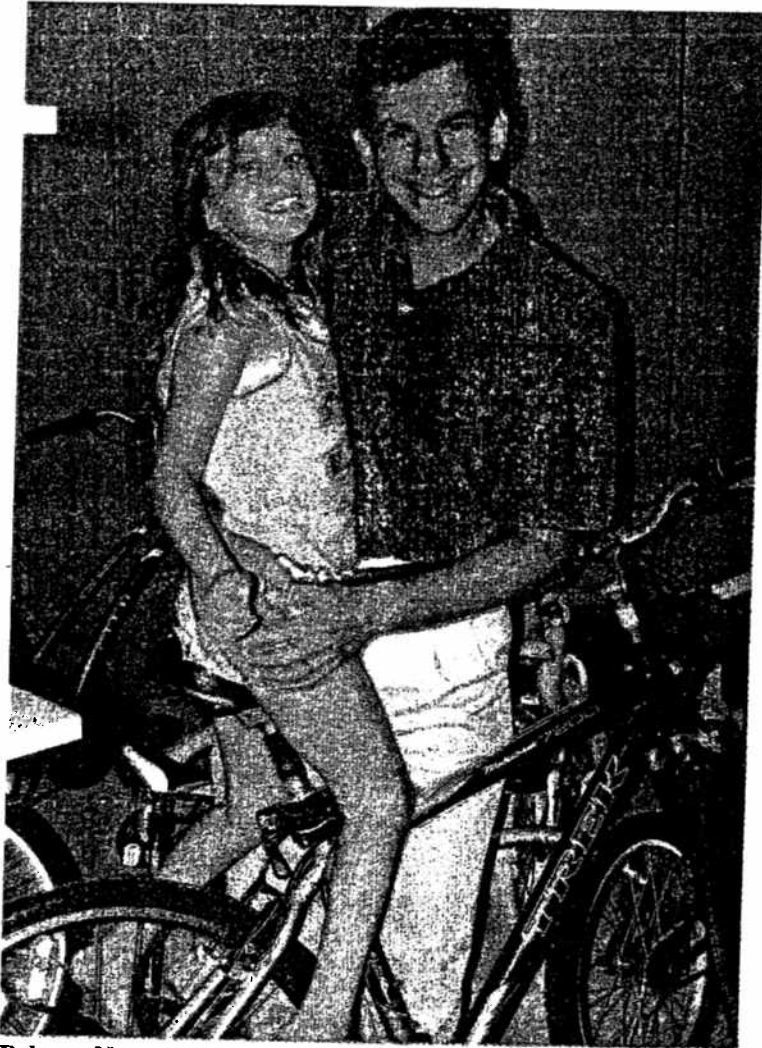
The gene causes dysfunction of the autonomic and sensory nervous systems from birth. It impacts the involuntary physical functions and causes unstable body temperature, wide swings in blood pressure, minimal sensation to pain, decreased tear production, delayed speech and walking, and difficulty or inability

to swallow. With improper swallowing, the liquid goes into the lungs and causes pneumonia and lung infections.

So, when Rebecca was hospi-

talized with six pneumonias before she turned one and her parents, Jeff and Lisa, knew the emergency staff at Westchester Medical Center by name, her parents became suspicious of

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Rebecca Newman and her dad Jeff, who will be riding in a bikeathon next month to help raise funds to find a cure for Familial Dysautonomia, the rare genetic disease from which she suffers.

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some genetic disease. But nobody knew what caused this and other developmental problems.

Finally, they met Dr. Felicia Axelrod at Dysautonomia Treatment and Evaluation Center at New York University Medical Center, a world specialist in FD, who diagnosed Rebecca and assigned her a number: 513. She was case #513 in the entire world. Today the number is in the 640s.

While Jeff and Lisa got tested for Tay Sachs before having Rebecca's older sister, Julia, 10, they knew nothing about FD, which only began to be diagnosed five years ago. "Julia was born perfectly fine and healthy," said Lisa. They didn't test after Julia.

"The amazing thing about Rebecca is she's got a very, very mild version," Lisa said. "We're lucky that she's so mild, we're lucky that she's so happy. We've been working so hard to keep her body strong and to keep her body healthy."

At summer camp, Rebecca saw other FD kids who had to sleep with oxygen and could only eat through the feeding tube, not the mouth. But, after exclusively using a feeding tube for liquids as a baby, Rebecca started to drink some liquids again at the age of four.

Rebecca is working hard to keep pace with other kids. She takes two kinds of blood pressure medications each day, gets liquid vitamins and supplements, and has to see more doctors and therapists than any of her peers. At Ridge Street School, where she just started third grade, Rebecca is accompanied by aide Joan Fleming to her classes and can't keep up with her friends playing soccer because she gets tired easily.

"When she's lying down, her blood pressure is higher than when she's standing up," her father Jeff added.

But Rebecca is happy. She rides a "yellowish-white" color horse in Connecticut to strengthen her posture, likes to show off her new bedroom and her school drawings, rides a bike with her dad regularly, and looks

up to her sister Julia.

"I think I treat her the best out of everyone 'cause I'm her older sister," Julia said, directly and simply. "If she's scared, she can come into my room in the middle of the night—I'll calm her down. She's the most ticklish person in the world. I'll tickle her and make her laugh."

Since Rebecca's illness, Lisa had to quit her job in advertising but went back to get her M.A. from Manhattanville College and is now working as an itinerant special education teacher, helping kids with developmental delays.

Jeff, who does credit card risk management for General Electric Consumer Finance, is also reaching out to the community.

To raise money for research into Familial Dysautonomia, Jeff will be riding in a bikeathon at Pace University in Pleasantville on Oct. 9.

The bikeathon started last year, when Jeff and 70 other cyclists rode 25 miles in 100 minutes and were able to raise \$50,000 for the Dysautonomia Foundation, a non-profit organization which supports medical research into FD.

The Newman family is asking residents and local businesses to sponsor Jeff and contribute as much as they can to find a cure. They are accepting all contributions, including sponsorship of a mile marker or corporate sponsorship.

For information on how to contribute directly or ride in the bikeathon for a \$25 registration fee, log on to www.fdcyclotour.org. You can also write a check made out to "Dysautonomia Foundation," indicate it's for the bike tour and send it to the Newmans at 48 Bonwit Rd., Rye Brook, NY 10573.

Jeff jokes that his Trek bike is "a hybrid bike for those older people—lots of shock absorbers." But he prepares himself by jogging every morning at 5:30 a.m. for five to six miles straight.

Meanwhile, as if anticipating the future of medical research, Rebecca has already chosen her life path. "I want to be a doctor," she said. "So I can fix people up."



Rebecca Newman and her older sister Julia.