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Rye Brook community comes together for a cure

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By Michael Scott Leonard

As a rule, a medical diagnosis you can't pronounce is dire news, conjuring ominous images of polysyllabic doom and gloom. Carcinoma, sarcoma, sclerosis, stenosis, fibrosis—these are not the words you want passing through your physician's lips.

So when doctors told Jeff and Lisa Newman 10 years ago that their then-infant daughter Rebecca's alarmingly frequent medical crises were caused by complications from Familial Dysautonomia, a rare genetic disorder peculiar to Jews of Ashkenazi (Eastern European) descent, the couple never imagined they and their two daughters would be leading essentially normal lives a decade later.

Familial Dysautonomia (FD) affects the sensory and autonomic nervous systems, impairing bodily functions such as respiration; swallowing and digestion; temperature and blood-pressure regulation; and sensitivity to heat, cold and pain. Despite dramatic medical advances over the past two decades, the disease can still be crippling—or even fatal.

But Rebecca—Patient No. 513 worldwide of about 600 diagnosed since the disease was discovered in 1949—is one of the lucky ones. She faces obstacles, but not limits, in her daily life. Although she takes most liquids through a feeding tube to avoid aspiration (fluid inhalation) which can cause choking or lung infections), Rebecca is, to all appearances, a normal preteen—right down to the braces, the stuffed animal and the older sister, Julia, she idolizes.

She began sixth grade last month at Blind Brook Middle School, an experience she described with a wide-eyed 11-year-old's quixotic moxie.

"It's exciting," she said during a recent interview at the Newmans' Bonwit Road home. "And scary."

Still, even Rebecca's comparatively mild case of FD has been life-altering for the family. There are the daily visits to occupational, physical and speech therapists. She participates in Pegasus, a horseback-therapy program designed to correct her posture and moderate her blood pressure swings. And though the couple is ever-grateful that Rebecca has managed to avoid FD's more severe symptoms and complications, the disease requires constant vigilance.



But the Newmans' fight against Rebecca's FD has also been life-affirming. They've taken the lead as tireless fundraisers—perhaps the most important of the unexpected roles FD has foisted upon them—and rallied the Rye Brook community around Rebecca's cause.

"The Dysautonomia Foundation was started about 50 years ago by the parents of afflicted children," Lisa said. "It's raised millions of dollars for research at NYU [New York University] Medical Center," home to the Dysautonomia Treatment and Evaluation Center, one of only two FD research and treatment clinics worldwide. "Because it's so small, it's really all up to the families. We don't have celebrities. [Rebecca is] only patient No. 513."

"It's not MS; it's not breast cancer; it's not like there's 10 people on every block who know someone with FD," she went on. "Around here, it's sort of just me going around asking people for support. We have letter-writing campaigns, a Bowl-a-thon, the bike tour. Medical research is tremendously expensive, and this small group of families has been able to double the size of the NYU research center."

To that end, Jeff and Lisa have become deeply involved—he as a participant, she as a principal organizer—with the annual Tour de Foliage, a 50-mile fundraising bike ride beginning and ending at Pace University in Pleasantville. The Tour, now in its fifth year, has raised more than \$400,000 to date for FD research—including more than \$50,000 so far this year, with the Oct. 12 ride still nine days off.

"Over the past four years, the Tour has picked up more riders and sponsors, recruiting mainly from Community Synagogue [to which the family belongs] in Rye and the Rye Brook community in general," Lisa said. "We've reached out to the community through word-of-mouth, advertisements, flyers, posters, e-mail lists, cycling newsletters, and the response has been overwhelming."

More than 200 Rye Brook residents have sponsored riders or mile markers each year so far—including, this year, the girl of the hour (and one of the Tour's *raisons d'être*).

"I sponsored Daddy for \$5," Rebecca beamed.

"We've also received a lot of support from KTI [Congregation Kneses Tifereth Israel in Port Chester]—where Rebecca and Julia attended preschool—and a lot of local stores have been so generous," contributing gift certificates and other prizes for riders and donors to win in the Tour's many raffles, Lisa said. Two of Rebecca's doctors even plan to ride this year.

The Tour itself begins with breakfast and ends with lunch; follows routes clearly indicated by arrows and signs; includes safety marshals aboard bikes and motorcycles, as well as emergency personnel on hand at all times; and provides toilets and food along the way.

"The amount of food we have—there's never been any risk of running out of food," Jeff said. "There are always extras, and we donate all extra perishables to the Carver Center" in Port Chester.

And FD's relative obscurity has its silver linings: With only about 100 participants each year, the Tour de Foliage is a much more intimate ride than the behemoth benefits often put on for breast cancer or multiple sclerosis.

"There's a lot less bike congestion and fewer cars along the way than at some other charity rides," Jeff said. "As a bike ride, it's a much more enjoyable experience."

Jeff will be riding with the Rye Brook Riders, a group of cyclist friends who have participated in every Tour de Foliage since they first came together four years ago—with Rebecca as a sort of honorary member and coach—to get into shape for the inaugural Tour. The Riders take part in charity rides throughout the area, but the Tour de Foliage is their flagship event.

"The Rye Brook Riders are a group of middle-aged dads who really hadn't done much riding before," Jeff said. "We started off training for the original Tour de Foliage four years ago, and we've recruited an expanding group. We ride from about 6:15 to 7:30 a.m. around the hills of Greenwich, which is a little bit easier than it sounds because of gears and bicycle technology."

"Biking is a great form of exercise for us because it's easier on the joints than running," he added. "And if you're ever struggling or worn out, you can lower your gear or coast."

But when it comes to their ongoing fight against FD, the Newmans are always in high gear. They remain determined to act on behalf of the entire FD community—particularly severely afflicted children whose lives can be ruled by unwieldy medical equipment and consumed by daily complications, including debilitating spinal curvature, frequent pneumonia and acute spikes or drops in blood pressure.

"It's important for us to remember that Rebecca has a very mild case," Lisa said, "and that we're incredibly fortunate to be raising her in such a supportive community."

The Tour has also fostered a sense of purpose among the Newmans' friends and the wider Rye Brook community.

"Our friends all volunteer," Lisa said. "They come with the children to help put together goodie bags—each rider gets a Tshirt, a water bottle and some sample products that were donated for the event. They help us assemble the goodie bags and drive them from Rye Book to Pace. It gets whole families— the whole community, really—involved on a very meaningful, personal level."

The Newmans half-expected this year's slow-motion economic collapse to crimp their fundraising efforts, but they remain on track to meet their goals.

"This is a tough year, with the economy the way it is, so every check is even more meaningful," Lisa said. "There's so much competition from other, very worthwhile causes, and for many people donations are now a real sacrifice. It means so much to us."

The Tour de Foliage includes 25- and 50-mile round-trip routes, with breakfast and lunch served at Pace before and after the ride, respectively. Check-in is at 8 a.m. for all riders, with the longer ride getting under way at 8:30 and the shorter trip beginning at 9. There is a \$35 registration fee, and all participants must raise at least \$75 in sponsorships (\$100 for those riding 50 miles). Those raising \$1,000 or more will receive free Tour de Foliage jerseys in appreciation, and anyone raising \$500 will be eligible to win an adult bicycle. Riders must be at least 18 years old.

To learn more about the Tour de Foliage or to sponsor a rider, visit www.fdcycletour.org or contact Lisa Newman at (914) 939- 3503 or ryenewlisa@verizon.net. To learn more about Familial Dysautonomia, visit the Dysautonomia Foundation Web site at www.famdys.org. To learn more about the Rye Brook Riders, contact Jeff Newman at (914) 939-3503.

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