

# Greenwich Time®

SERVING THE COMMUNITY SINCE 1877 • FRIDAY, MAY 16, 2003

## *Family starts trust to fight genetic disease*

By Ivan H. Golden  
Staff Writer

©Southern Connecticut Newspapers, Inc.  
All Rights Reserved.

When she entered Parkway School four years ago, Dana Marella appeared to be a somewhat clumsy but otherwise healthy child.

In home movies, Dana can be seen dancing, swimming and climbing a jungle gym. But in the few years since those videos were filmed, Dana's physical and mental condition has rapidly deteriorated.

Today, Dana, now 9, walks gingerly and uses a walker in school. She suffers from dementia, and her speech is limited to monosyllabic words.

A little more than a year ago, Dana was diagnosed with Niemann-Pick Type C, an incurable genetic disease that affects a few hundred people nationwide, nearly all of them children.

There is no treatment, and most NPC sufferers die in their early teens.

"You're basically told, 'Enjoy your child, because you have a limited amount of time with her,'" said Philip Marella, Dana's father.

But the Marellas were not content to watch as their daughter's mind and body eroded.

Last fall, the family founded Dana's Angels Research Trust, which raises money for medical research on NPC. The charity will hold its first public event tomorrow.

About 130 Parkway students have already signed up for "DART to the Finish," a short run scheduled for 11 a.m. tomorrow at Parkway School. Each runner obtained sponsors, and several hundred Parkway parents and family members have pledged donations to DART.

Since its foundation, DART has raised \$75,000. Because the disease is so rare, however, the Marellas said DART and other NPC research organizations have found fund raising difficult.

The nation's largest NPC fund-raising organization, the Ara Parseghian Medical Research Foundation, has raised \$18 million since it was founded in 1994, according to its Web site. The foundation, named for the former Notre Dame football coach, whose grandchildren suffer from NPC, coordinates with DART.

"I thought (\$18 million) was a lot of money, and it is," Philip Marella said. "But when you start talking about genetic research, that's nothing."



(Mel Greer/Staff photo)

Dana Marella, center, has an incurable genetic disease that her parents, Andrea, left, and Philip, right, are fighting through Dana's Angels Research Trust. The Marellas started the trust to raise money for medical research of Dana's disease, Niemann-Pick Type C.

Andrea Marella said DART hopes to enlist a celebrity spokesman who might generate more interest in the disease.

"This is so much more urgent," she said. "The clock is ticking for these kids."

NPC is a recessive genetic disease caused by a mutation on chromosome 18.

In healthy people, cholesterol enters a cell and is broken down and used for fuel. Excess cholesterol then passes out of the cell. With NPC sufferers, however, it cannot escape. It accumulates and eventually smothers the cell. NPC is particularly devastating to the brain, liver and spleen.

Oxford Glycosciences PLC, a British biopharmaceutical company, is in the midst of human trials for a drug to treat NPC, according to a spokesman for the company. The trials have shown some success at slowing the disease's progress.

So far, the trials have been on children age 12 and older, but the company is expected to begin a trial on younger children this summer. The Marellas hope Dana will be healthy enough to participate.

In the meantime, the family is trying to keep a positive attitude. The Marellas point out that Dana is, despite her condition, a happy child with several friends at Parkway School. She has a dazzling smile, and she smiles often.

As NPC takes its toll on her brain, however, Dana's intellect has suffered. A fourth-grader, she now attends mostly special education classes. The Marellas hope Dana can somehow retain the basic math and reading skills she has learned until there is an effective treatment for the disease.

"If we can just keep her where she is, who knows?" Philip Marella said. "Maybe we'll be able to fix her, too."

Contributions to DART may be mailed to Dana's Angels Research Trust, 15 E. Putnam Ave., #117, Greenwich, CT 06830-5424.