

Fighting back

As a rare disease stalks their young son, Hoosier parents seek private funds for clinical trials of gene therapy.

BY T.J. BANES
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When disease invades a family, it forces everyone into survival mode.

And with it often come feelings of social and emotional isolation.

"It was like we were all alone on an island. It was us against this disease. At first, even our family and friends didn't know what to do to help," said 32-year-old Phil Milto.

Two years ago, Phil and Tricia Milto's son Nathan was diagnosed with Batten disease, which attacks the nervous system and is always fatal. It is diagnosed in three of every 100,000 children born in the United States.

In a matter of months, Nathan, now 6, once a bright, athletic, outspoken preschooler, lost his sight, his ability to speak clearly and many of his motor skills. He now is a primary student at the Indiana School for the Blind, and receives most of his medical care through occupational, speech and physical therapy there.

Nathan's parents spend each day hopelessly loving the dark-haired, dark-eyed little guy, whose life expectancy is 10 to 12 years.

"We were told to contact a parent support group and to learn to cope. We're not coping and dealing," said Phil Milto. "We're doing something; we're doing all we can. We're all he's got."

For the Miltos that means making Nathan as comfortable and as secure as they can.

Today, Nathan seems happiest when tuning into the things he remembers from his toddler years — when he could see and laugh with his favorite Disney videos and sports heroes. On his sixth birthday, Nathan believed he was turning 2.

As he regresses physically and cognitively day by day, his parents know there is no

federally approved drug that can stop this disease. In time, Nathan may no longer be able to enjoy shooting hoops (his parents bang on the backboard so he can hear where to shoot) with his dad, or eating pizza with his family. He may be bedridden and dependent on a feeding tube for nourishment.

Because there are so few experts in Batten disease, Nathan doesn't even have regular doctor's visits. There's no reason to — the doctors can't do anything for him. His therapy at the Indiana School for the Blind has done him the most good, his parents say.

"The best historian for a child's well-being is his parents," said Nathan's pediatrician, Dr. Gregory Smith. "There wasn't anything concrete from an exam, but his parents noticed a change."

Just as family members struggle to make sense of Batten disease, Smith has to cope with the challenge of serving a patient diagnosed with a rare illness.

Smith first checked Nathan at the age of 4 when his mother felt he was regressing in basic skills. Soon afterward, he began to lose his sight. He underwent a battery of tests and was fortunate in that his neurologist at Riley Hospital for Children had seen about 12 cases of Batten disease.

Smith compares the debilitating illness to Alzheimer's disease in that Nathan is slowly losing touch with the environment and the people he knows so well.

"This is the closest I've ever come to this type of sickness, and I will probably never have another patient like this," said Smith.

Beyond basic health care, Smith's hands are tied.

"I do a lot of phoning and researching, and I find quite a few physicians who aren't familiar with Batten disease," he said. "In our

major medical journal, there are only about four sentences. Even genetic experts I know talk about how unusual it is."

Dealing with a child who has a terminal illness makes everyone re-evaluate their roles.

"The family is the framework for the way in which a child adjusts to the illness," said Andrew Harner, a clinical coordinator for Riley Hospital's social work services who often counsels families like the Miltos. "Families come to us with their own coping mechanisms in place. We try to enhance those coping mechanisms."

That coping can take many forms. For many parents, the first line of defense is academic — to learn all they can about the disease. Harner said this approach is much healthier than emotionally shutting down and closing off from outside support.

"You have to respect and value each person's coping mechanisms, whether it's right or not, but you want to encourage them to stay focused. We are constantly re-evaluating a family's needs."

Harner encourages families to allow the child to give them cues.

"Sometimes they just want to be a normal kid. They don't always think about what their life could have been; they think about what their life is now."

For Tricia, 32, a recent visit to her son's school meant coming to terms with Nathan's independence.

"It was so tough to let him go, knowing that our days are numbered."

At first, Tricia followed her motherly instincts by picking Nathan up from school two days a week. It was her way of keeping in touch with his teachers and, most of all, with Nathan. But after a while, she backed off.

School is a familiar and safe place for Nathan. From his Greenwood home, Nathan gets on a school bus every weekday morning at 6:10 and doesn't return until 4:30 p.m.



"It's such a long day, and I hated being away from him," says Tricia. But when she picked Nathan up, he protested, insisting that his mom let him ride the bus. She relented, but sometimes secretly follows the bus as she fights to let go.

"I was doing what was best for me. He is happy here," she says, peering in from the doorway of Nathan's classroom. Nathan doesn't even know she is there as he sings out loudly, whistles and stomps to *The Good Morning Song*.

In classroom No. 120, Nathan is one of Nancy Bingham's "shining stars." He plays with a guinea pig named Scooby Doo, learns the days of the week and the seasons of the year, plays ball in physical education, eats lunch in a cafeteria and has friends named Jacob, Skylar, Drew and Lincoln.

"With Nathan, our main goal is to help him continue having enthusiasm for school. He has some pretty big obstacles ahead of him but he needs to have fun and learn along the way," Bingham said.

When he comes home at the end of the day, he shares his two-story brick home in a quiet Southside suburb with his parents, his younger brothers, Nicholas, 4, and P.J., 3, and his black Labrador, Mia.

Tricia admits frequently worrying about the development and behavior of Nathan's two younger brothers. "Is Nicholas acting out this way because of his brother's illness, or is this just typical middle-child behavior?" she asks. "Are P.J.'s speech difficulties early signs of bigger problems, or is it just his age?" While she second-guesses herself, Tricia continues to resist testing Nathan's two younger brothers for Batten disease. She says she has about all she can cope with right now.

"The hardest thing with me is that I'd like to dedicate every minute of every day to Nathan, but I have two other children who need me," said Tricia.

This often is the time other family members find their new roles.

Opting for early retirement from Eli Lilly and Co., Tricia's mom, Wilma Evers, sold her Downtown home, and she and Tricia's

stepfather moved to the Southside — two minutes from the Milto — to be closer to their grandchildren.

Almost daily, Evers can be found pushing Nathan on the swing, helping around the house, or listening as her daughter pours out her heart.

"I'm doing exactly what I want to do and what the Lord wants me to do," Evers said. As she holds Nathan on her lap, he pretends to snore. His humor makes his brothers, grandmother and mother laugh aloud.

Tricia says: "I'm thankful I can still tickle Nathan and hear him laugh, but I sure do miss the eye contact. I'd love for him to look me in the eyes again."

Phil Milto stayed on the academic path to coping.

He spends countless hours studying and researching Batten disease and raising money to fund the clinical drug trial of a potential cure — a form of gene replacement therapy.

Clinical drug trials for common diseases almost always are conducted and funded by pharmaceutical companies and large teaching universities. The rare diseases often don't garner the attention needed to make new drugs. Phil is trying to change that.

"There are many days that I think, 'Nathan was supposed to be my all-star basketball player; this wasn't supposed to happen,' " said Phil. "When I realized I'm just lucky to have him, forget basketball, I decided I had to separate the emotion and develop a business plan."

He relies on his business degree and training at his family's dry cleaning operation to guide him.

"We wonder if God has done this for a reason," said Phil. "Tricia has experience in event planning that will lead us toward raising funds, and she has always had an interest in special-needs children. I have the background in management and business to help move us toward a cure."

Even so, Phil and Tricia often find themselves living in different worlds.

"I'm busy shuttling the kids around, and Phil's got the research stuff going on. He

interacts with so many people every day that sometimes we don't even talk about it. We both have bad days, but fortunately, it's usually on opposite days," said Tricia.

"Phil copes by being proactive . . . finding a way to make the situation better or to change it," said Denise Sedgwick, a family friend. "Tricia copes by making the kids' childhood as normal as she can. In the beginning, it was a lot of denial. They've definitely reached the acceptance level and are making the best of every day."

Asking for help is the most important way a family can get off of their island, and become connected with a support network, said Dr. Megan Abshir, medical director of St. Vincent Hospice. "People are willing to help, but you have to guide them. It's like a funeral. When people say, 'Call me if you need me,' you have to think of specific things they can do to assist you. Ask them to pick up the kids from day-care or throw in an extra load of laundry."

Sedgwick, along with a number of other friends and relatives, have been a part of various projects involving Nathan to promote awareness of the disease. They have been hosts of a dinner, golf outing and circus event to raise money in support of the private sponsorship of a clinical trial for gene therapy.

Even Nathan's neighborhood pals have gone door-to-door raising funds while wearing T-shirts in support of their sick friend.

Sedgwick said once the Milto made it known that they were working toward a federally approved therapy, their friends had a goal and a direction.

"At first we felt helpless, and when we asked what we could do, it seemed like so little compared to the challenges they faced," said Sedgwick. "A lot of people sometimes distance themselves. It's not done because they don't care, it's because they don't know what to say and they don't want to say the wrong thing. . . . Sometimes all it takes is being there and listening."

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