PEOPLE

A boy who'll be 'forever in my heart'

A 3-year-old born with Tay-Sachs inspires his parents to ensure a legacy helping others

By Susan Weidener
INQUIRER SUBURBAN STAFF

Brian and Sherri Manning know time is running out, but have refused to give up hope. The parents of a 3-year-old, Dylan James, who has Tay-Sachs disease, the Mannings look at their son and find the determination to go on with a mission.

Brian Manning said Dylan's strength motivates and energizes him even as he and his wife watch their only child suffer seizures and blindness.

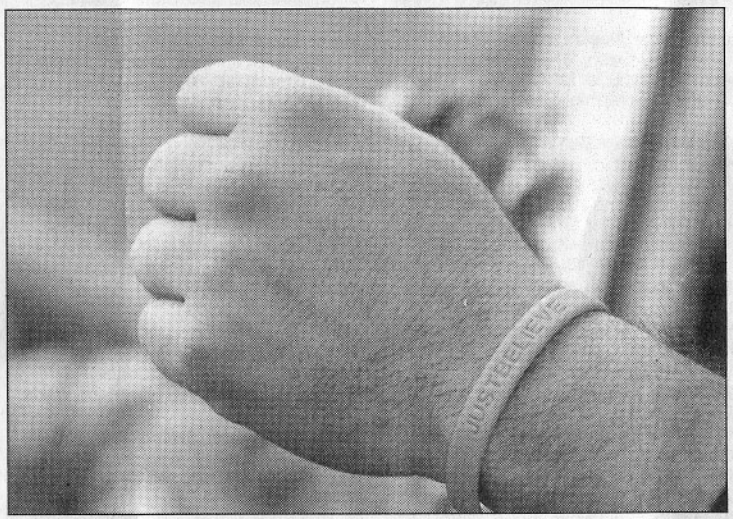
"Dylan gives me my strength," says Brian, 33, who works in human resources at QVC. "I feel I need to live my life for him. He keeps me focused."

"For a little child to go through this as heroically as he does, he gives us every reason to wake up in the morning," Sherri Manning says.

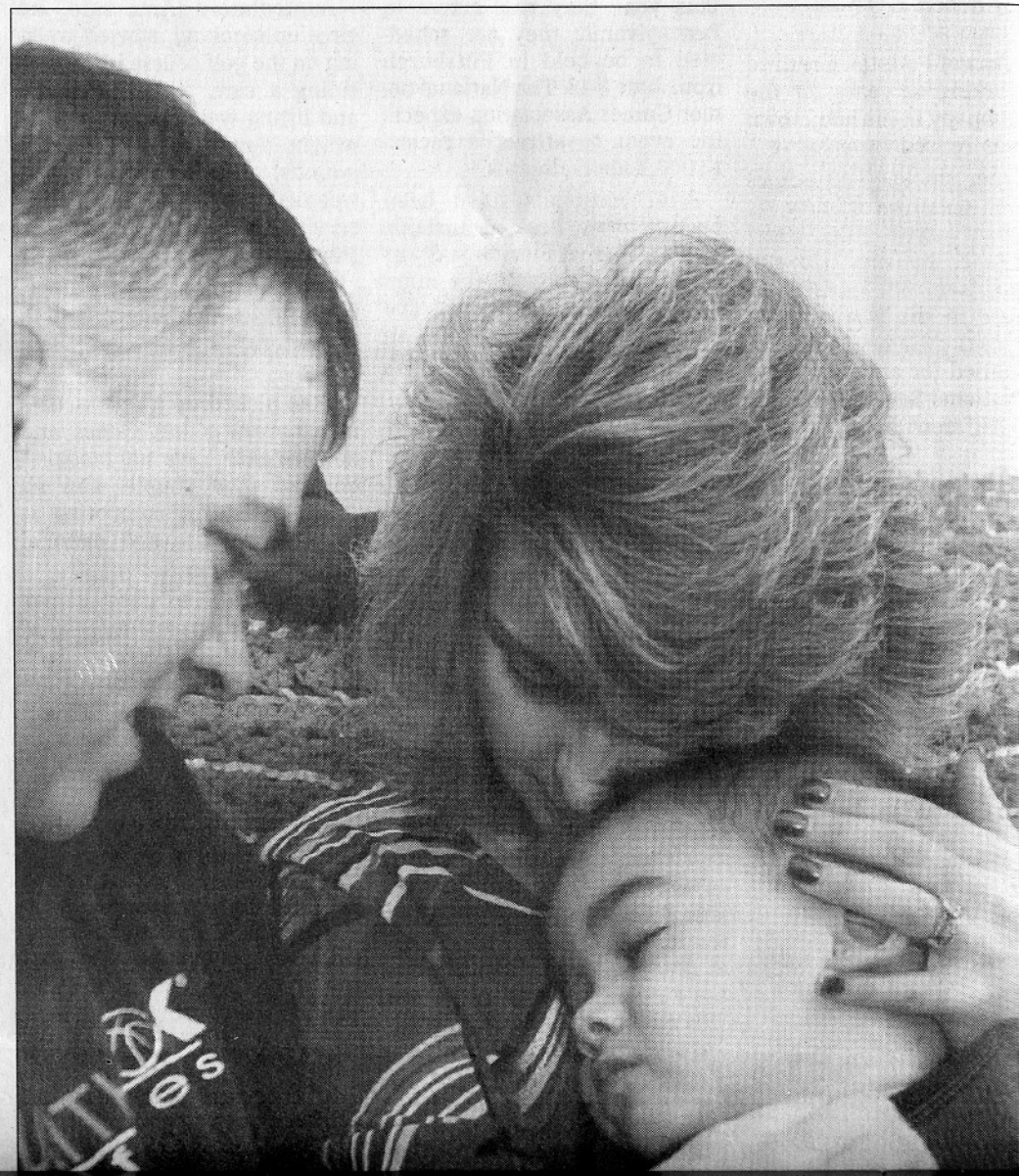
The Chester County couple started the Dylan James Manning Foundation, an affiliate of the National Tay-Sachs & Allied Diseases Association Inc. in Boston.

"The Mannings have been incredibly committed to Dylan and want to increase public awareness and funds," said Jayne Gershkowitz, executive director of the association. "They realize now that this is a cause bigger than Dylan. It is Dylan and all the other people and children dealing with this disease or [who] will be dealing with this disease."

Tay-Sachs is a genetic disor-



Brian Manning wears a "Just Believe" bracelet, which is being sold to raise funds for Tay-Sachs disease. The Mannings did not fit the typical genetic profile for parents of a Tay-Sachs baby.



More About Dylan

On their Web site, Dylan's parents write about their son's battle with Tay-Sachs:

"Dylan never sat on his own, was unable to stand for more than a few seconds and never spoke a word other than 'MOM,' which he still verbalizes! Dylan is not able to walk or talk, he has a feeding tube in his belly for nourishment, and he cannot see his mommy or daddy anymore. He is not able to move his own arms and legs, but he loves to be cuddled and kissed gently. Dylan no longer laughs or cries, but occasionally he gives us an encouraging smile to let us know that he is OK. He has seizures very frequently (5 to 10 times daily), and usually passes out as a result."

To Help Fight Tay-Sachs

"Believe" bracelets ($2) and "Dylan's Heavenly Delights" cookbooks ($20) can be ordered online at

cookbooks ($20) can be ordered online at www.djsfoundation.org. Donations can be made on the Web site or mailed to DJ's Foundation for Tay-Sachs Disease, P.O. Box 1444, Exton, Pa. 19341.

Tay-Sachs is a genetic disorder in children that progressively destroys the central nervous system. There is no cure; life expectancy is usually 2 to 5 years.

Gershkowitz said a small research study including children under 2 with Tay-Sachs was starting at Children's National Medical Center in Washington.

The Mannings "have been working very hard in their community to explain Tay-Sachs and dispel myths about the disease," she said.

About 30 to 35 new cases of Tay-Sachs in children are reported yearly in North America, although accurate numbers are hard to come by, according to the association. Although one of 250 people in the general population are Tay-Sachs carriers, it seemed unbelievable, the couple said, that they both would be carriers.

Carriers are mostly of Eastern European Jewish descent and non-Jewish French Canadians. The Mannings, Catholics, went through four miscarriages before they carried Dylan to full term. They were devastated to learn in March 2003 that their only child had a disease neither had heard of before the diagnosis.

And neither had any idea they could be carriers. Brian is of Irish and French-Canadian descent, but after research, Sherri discovered her grandmother was from Eastern Europe.

The Mannings, who live in Atglen in western Chester County, started the Dylan James Manning Foundation to educate and fund research for a cure for Tay-Sachs, almost the day after Dylan was diagnosed. His story can be found on his Web site, www.djsfoundation.org.

The Mannings, who were high school sweethearts at Bishop Shanahan and got married in 1998, said all they ever wanted was a family.

As a little girl, Sherri Manning dreamed of having a baby.

"I used to ask the tooth fairy for a baby instead of money."

Sherri, 33, is pregnant again. The couple had in vitro fertilization after working with doctors to ensure that Sherri's egg did not carry the Tay-Sachs mutation. Brian's mutation is not identifiable, they said.

The baby-to-be is a source of bittersweet happiness for the Mannings. They have already decided on his middle name: Dylan.

If they can't save Dylan, then they want to help others like him. And the response has been "overwhelming," they said, as the story of Dylan James gets told.

More than 40,000 of light-blue bracelets, bearing the words *Just Believe* and Dylan's name and costing $2, have been sold in 20 states and three other countries. The Mannings recently put in an order for 100,000 more bracelets, and schoolchildren throughout the region have been packaging and buying them. Candles and cookbooks also have been sold in Dylan's name.

There is a signed baseball from Boston Red Sox pitcher Curt Schilling. (Brian is from Boston and a Red Sox fan.)

So far, $50,000 has been raised at local schools, from the Internet, and from other fundraisers. The goal is $1.5 million — money needed to help fund clinical trials that could save children such as Dylan with Tay-Sachs.

"We rattle our brains day in and day out," said Sherri Manning, a former comptroller at the Church Farm School in Exton. "We want to get a musician like Billy Joel or Barbra Streisand and raise a lot of money through one concert."

Meanwhile, the little boy with the bright blue eyes is very sick.

"His health is deteriorating. We live every day with him as though it is the last," Sherri Manning said.

Brian Manning likes to say Dylan has what parents of children with Tay-Sachs call "the face of an angel."

"The faces of children with the disease all look the same," he said. "They have no lines; just a kind of glow."

The fact that he is expecting another son only adds, he said, to his feelings of dedication to Dylan.

"Dylan," Brian Manning said, "will be forever in my heart."

BOB WILLIAMS / Inquirer Suburban Staff

Brian and Sherri Manning cuddle with their son, Dylan, 3. "We live every day with him as though it is the last," Sherri says. Sherri Manning always dreamed of having a baby. "I used to ask the tooth fairy for a baby instead of money." As Dylan battles Tay-Sachs, Sherri is expecting another boy.

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