

North Pinellas Times

tampabay.com

Sunday, August 19, 2007 | NPN



TED McLAREN | Times

Jeremy Keyser, 6, who was diagnosed with hydrocephalus as a baby and endured surgeries, laughs with his parents, Paula and Mark, in their Largo back yard late last week.

Their support for son launches goal

The parents' effort to learn more about his condition leads to a pilot expansion program.

BY RITA FARLOW
Times Staff Writer

LARGO — When Mark and Paula Keyser learned their infant son was born with a condition that causes an abnormal build-up of fluid in the brain, they longed to talk to other parents in the same situation.

Trouble was, there wasn't a local group to turn to for support and advice about the condition, called hydrocephalus. So the couple reached out to other families

through their pediatric neurosurgeon's office and started their own informal group.

Paula Keyser said the key to starting the group was "to try to find other people, other families, who could relate to the things we had been through."

About 25 people showed up for their first meeting, a picnic the Keyzers hosted at their home in April 2004. The following year, the group organized a walkathon and raised more than \$4,000 for the

national Hydrocephalus Association, based in San Francisco.

Earlier this year, the group was one of two selected by the national Hydrocephalus Association to participate in a pilot program for regional expansion. They held their first official meeting as a regional affiliate for the national organization in April.

"Our objective is having local groups in every state," said Dory Kranz, executive director of Hydrocephalus Association.

The organization's goal is to create a network of affiliates that can

» See **SUPPORT, 5**

St. Petersburg Times

Sunday, August 19, 2007

Parents' efforts extend far beyond their son's condition

share resources and unite in lobbying efforts for research funding, Kranz said.

Hydrocephalus is a condition that can be acquired as a result of meningitis, head trauma, tumors and cysts. A congenital form affects one or two of every 1,000 live births, said Dr. Sarah J. Gaskill, pediatric neurosurgeon at All Children's Hospital in St. Petersburg.

"It can affect anyone of any age," she said.

Hydrocephalus is not curable, but is commonly treated by inserting a shunt into the brain, which is connected to a tube to drain excess fluid.

"It's our most common operation as a pediatric neurosurgeon. We will perform six to 10 new or re-operations (on shunts) per week," Gaskill said.

Jeremy underwent three surgeries before he was 6 months old to insert and repair his shunt, but some children with the condition undergo dozens of operations before they reach their teens.

The Keyzers said they've been fortunate that Jeremy's shunt works properly. Now 6 years old, Jeremy will start kindergarten this year at McMullen-Booth Elementary in Clearwater, where his dad is a teacher's assistant.

"He's progressing wonderfully. He started out developmentally delayed and I think he's really close to being caught up to his age," Mark Keyser said.

He credits his wife with being the driving force behind the support group.

"She's very determined when she sets her mind to something like that. She won't stop until she gets it done," Mark Keyser said.

All of the hard work, he said, has been worth it.

"I don't think we've ever done any of it just to benefit Jeremy, although that's certainly an underlying reason," he said. "But it's always for the greater good for others who might have to go through some of the same things we've gone through.

The Keyzers aren't done yet. Paula Keyser said she'd like someday to take a leadership role within the national organization.

"If we've just accomplished this, I know it can be so much more," she said.



Photo courtesy of the Keyser family
An X-ray of Jeremy Keyser in July 2006 shows the shunt series (thin, curved line) that has been inserted into his skull.



TED McLAREN | Times
Pins and ribbons, which Paula Keyser made from the same tubing used to make shunts, sit on the family's table. They will be used at a fundraising walk at Largo Central Park on Sept. 2.

» IF YOU GO

Hydrocephalus Association Walkathon

The Hydrocephalus Association Tampa Bay Affiliate will hold its third annual local TEAM Hydrocephalus walkathon beginning at 9 a.m. Sept. 2 at Shelter No. 1 in Largo Central Park, 101 Central Park Drive. The group is still seeking donations, and sponsors for T-shirts, food and water for the picnic that will be held after the walk. For information, call Paula Keyser at (727) 637-5585 or visit the Web page at www.gohydro.org.

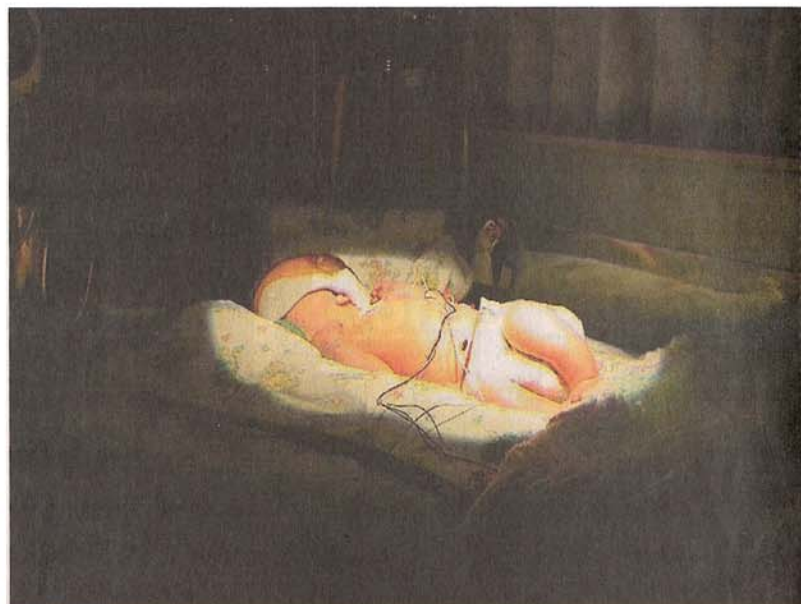


Photo courtesy of the Keyser family
A newborn Jeremy Keyser lies under bilirubin lights to combat jaundice at the neonatal intensive care unit at All Children's Hospital in St. Petersburg in July 2001.



Jeremy Keyser, 6, swings with his dad, Mark, in the family's Largo back yard on Friday afternoon, August 17, 2007. His parents, who started a support group after Jeremy was born, reached out to the national Hydrocephalus Association. The couple received some funding from the parent organization.

TED McLAREN | Times

St. Petersburg Times

Sunday, August 19, 2007