

Twins in a fight for their young lives

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SHERMAN OAKS - Ethan and Keane Denke are too little to know the big name of the disease that causes their livers to swell, or their temperatures to frequently spike to 103 degrees.

The twins are too young to understand the panic their mom and dad experience each time they rush their sons to the hospital.

"To look at them, you wouldn't think they were sick," said Xander Denke, the boys' father. "They have big smiles in between chubby cheeks from the drugs."

Just 9 months old, Ethan and Keane have been diagnosed with hemophagocytic lymphohistiocytosis, a rare genetic disease that affects 1.2 out of 100,000 babies.

"The body's big (white) cells become out of control and start engulfing the red cells," said Dr. Neena Kapoor, clinical director for the transplant program at Childrens Hospital Los Angeles. "The babies become anemic, their livers start getting big and they require blood transfusions."

To keep the disease under control, Ethan and Keane endure chemotherapy once a week.

The only cure is a bone-marrow transplant. The boys' parents are not a match, and the chance of finding another donor with compatible marrow is about one in 20,000.

"Without the bone-marrow transplant, it's fatal," said Jeff Toughill, president of the Histiocytosis Association of America, a New Jersey-based nonprofit that has funded more than 100 research projects.

Toughill founded the association about 20 years ago because his baby girl had a similar disease.

Because HLH is rare, the federal government has listed it as an orphan disease - one that affects fewer than 200,000 people - so it does not qualify for major funding, Toughill said.

And doctors have only begun to diagnose it within the past 15 years, thanks to the research funded by Toughill's association.

This year, four cases of HLH were diagnosed at Childrens Hospital, proof that the process has improved, Kapoor said.

About 200 people are part of Toughill's association, which is meeting today in Florida for its annual convention.

The Denkes learned their children had HLH after Ethan suffered a fever of 103 in February and was taken to Tarzana Medical Center, where he was hospitalized for two weeks. In April, Keane was hospitalized with similar symptoms.

"They are being kept alive because of chemotherapy and immune-suppressing drugs," said Conrad Denke, the twins' grandfather. "If they didn't suppress the immune system, it would kill them."

The boys are kept at home much of the time, secluded from the germs in public that can invade their bodies easily and make them sick, Conrad Denke said.

In the meantime, several bone-marrow drives have been planned for the San Fernando Valley. One drive in Arcadia this week resulted in 157 swab tests from potential donors.

But the need to find a match is dire, Conrad Denke said.

"It's like a ticking time bomb," he said. "It's devastating."