

GREGORY'S LEGACY

GRANITE BAY COUPLE HAS
RAISED MILLIONS IN HONOR
OF THEIR SON

STORY BY
**Jamie
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After losing their son to Gaucher disease, Greg and Deborah Macres worked hard to preserve their little boy's memory and keep his legacy alive.

In the process, the Granite Bay couple has raised more than \$1.5 million, attracted the attention of doctors and families battling the same disease worldwide and helped fund research that will help at least 26 other lysosomal diseases.

This was all accomplished through the Children's Gaucher Research Fund, a nonprofit organization incorporated in 1999 to honor their son's life and find a cure for the disease that took him.

"I would have preferred to not have lost a child ... but the thing is it happened," said Greg. "The reason we

(organized and continue running the foundation) is my son's legacy. He may have had a short life of four years but he can still do something to fight this disease. We want his life and the disease to be a more positive thing and we have the ability and the motivation to do it."

Shortly before their son's first birthday, little Gregory, was diagnosed with Gaucher disease Type 3. Gaucher (pronounced go-shay) disease is a rare inherited metabolic disorder whereby the body cannot rid itself of worn out red and white blood cells, which begin to store in the liver, spleen, bone marrow and sometimes the heart and lungs. In children's cases, all of the above symptoms exist, but the disease is also characterized by such neurological signs as strabismus, ocular motor apraxia, and problems with breathing, swallowing, motor skills and balance. Speech and cognitive developments can also be delayed.

According to statistics, the disease occurs in 1 in 100,000 births.

When he was first diagnosed, Greg remembers ask-

ing the doctors what the disease was exactly doing to his son's brain?

"They told us they didn't know," Greg said. "We asked them, who is doing research on this disease, and we could tell by their body language that the answer was nobody. So here we are dealing with a rare, orphan disease."

At age 4, their son received a bone marrow transplant. Ten days later he died on April 13, 1997.

"At Gregory's memorial, people were writing out checks for research and we quickly set up the fund for that," Greg explained.

The couple and their oldest child, daughter Ashley Rose, 6 at the time of her brother's death, moved from the Bay Area to Granite Bay in 1998. The fund was incorporated into a nonprofit the following year.

"Our goal is very simple: To raise money for Gaucher research and to find a cure, period," Greg said.

The research funded by the Macres' foundation has had overlapping benefits on a host of other lysosomal diseases that affect the brain, such as Parkinson's



COURTESY

Gregory Macres, on his first day of pre-school. Gregory died at 4-years-old of Gaucher disease, Type 3.

and possibly Alzheimer's.

"All of a sudden, our scope got bigger," Greg said. "The research we are funding can be used to research the cause of 26 other diseases. It kind of went from this small orphan disease to this bigger and broader scale."

The Macres run the foundation from its "world headquarters," or their home office, Greg explains with a chuckle. He and his wife don't get paid for their work and promise that 100 percent of all donations go toward research to find a cure.

"We do have expenses, but we pay for them," Greg said. "If I'm going to ask my friends, my colleagues, everyone I know to donate to this, I want to make sure 100 percent of it is going to research. I don't think there's a charity out there that can say that."

Money is raised through fundraisers, like Florin High School's Awake-A-Thon that's raised \$50,000 in the past five years, and the Gregory Austin Macres Memorial Golf Tournament that was held at a Bay Area golf course. In June Greg was still talking with former Sacramento King Vlade

Divac about hosting a second fund-raising event this summer.

But the donations Greg says he's most proud of are the personal ones.

"The most amazing thing is the people who just pitch in and help with things," Greg said. "People send us \$30, \$50 and \$100. We never thought it would be so successful."

"Gregory's legacy has been a focus for a cure," adds Susan Nelson, who does public relations work for the foundation.

The Macres currently live in the Hidden Lakes community of Granite Bay with Ashley Rose, now 17, their adopted children, son Matthew, 9, and sisters Victoria, 7, and Nicole, 6, and the family pets, a dog named Chassa and a cat named George.

Eleven years after little Gregory's death, the couple is still as dedicated as ever in finding a cure and honoring their son's memory.

"It's my nonpaying job," said Greg, an executive for Coldwell Banker.

— For more information or to make a donation, visit www.childrensgaucher.org.



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Deborah Macres, left, Greg Macres and Bobbie DeFacci at the 2008 Conference. DeFacci lost her 2-year-old son Joey DeFacci to Gaucher disease in 1996.