

## Children's Gaucher Research Fund

# Remembering Gregory

By Anne Gonzales

**I**n 1994, Greg and Deborah Macres were told their 11-month-old son, Gregory, had a rare incurable genetic disorder that was frequently fatal. Little was known about the disease, and almost no treatment was available. Three years later, their blond, cherubic preschooler died from complications of a bone-marrow transplant.

"When your child is sick, you devote your life to saving him," Macres says. "Then when he's gone, there's no more medicines in the refrigerator, no more chest tubes, no more doctors' appointments. I felt like I got fired from my job."

Today, the Granite Bay couple has filled that void. They are committed to finding a cure for their son's killer,



[childrensgaucher.org](http://childrensgaucher.org)

Gaucher (pronounced GO-shay) disease.

At Gregory's memorial service, family, friends and business associates started writing checks, but there was no fund to receive donations for Gaucher research. Greg and Deborah created the Children's Gaucher Research Fund, and in seven years, the foundation has raised more than \$1 million for research on lysosomal diseases, which





“Every morning at 5 a.m., when I sit down at the computer, I know why I’m doing it. This is our son’s legacy.”

— Greg Macres, president and founder, Children’s Gaucher Research Fund

are characterized by an inadequate functioning of enzymes in the body’s cellular structure.

Greg, senior vice president of Coldwell Banker NRT’s western region office in Roseville, and his wife, Deborah, formerly a neonatal intensive care unit nurse, spearhead fundraisers, including golf tournaments and private dinners with Vlade and Ana Divac, and organize scientific conferences. The couple

maintains a website, puts out a newsletter and tries to answer questions from frantic parents around the world.

#### 100% to Research

The foundation now has 17 families who share their stories to help raise awareness and research money. The founders say 100 percent of the donations go to medical trials. “Every morning at 5 a.m., when I sit down at the computer, I know why I’m doing it,” Macres says. “This is our son’s legacy.”

The foundation has already funded the study of an Israeli scientist who discovered how the disease attacks the body. Now, there’s evidence that the gene mutation in Gaucher disease may be linked to Parkinson’s disease.

Kids with Gaucher are perfectly healthy in every way except for the deficiency of an enzyme responsible for breaking down dead cells to be eliminated by the body. Without it, the cells build up in various parts of the body, in the liver, spleen, lungs, lymph system and the central nervous system. Lysosomal diseases affect about one in 7,000. Gregory’s disorder, Gaucher Type 3, is a severe form that affects not only organs but the brain, as well, occurring once in every 100,000 births. Both Greg and Deborah carry a recessive gene for the disease.

Raphael Schiffmann, a lead investigator for neurological disorders at the National Institutes of Health in Bethesda, Md., cared for Gregory,




Greg and Deborah Macres listen to a presentation during a June research conference they organized in Sacramento.

and now recognizes the importance of the foundation's work. Before the foundation, no one was fundraising for Gaucher, he says. What's more important, the biennial scientific conference organized by the Macres is "the only one of its type to look at lysosomal disorders and their effect on the brain," Schiffmann says. This year, the two-

At the time of Gregory's bone-marrow transplant, it was the only treatment for his type of Gaucher. Replacing all his marrow with someone's healthy cells could help him start manufacturing the deficient enzyme. A donor was found, and Greg and Deborah drove their son to the University of Minnesota. The transplant was

successful, but Gregory developed an infection and died several days later.

"This family suffered a tremendous loss, and they are now using their energy to try to prevent this fate from happening to other patients," says Schiffmann.

Greg and Deborah have since adopted three children. Greg says he understands that the research won't help Gregory, but it's a way for the couple to honor their son and continue to make his life worthwhile. "The harsh reality is, the fact that we lost our son to this disease opens more doors; it makes people listen to us," Macres says. "We can either throw that away or do something with it." 

**NEWS TALK**

---

**1380 AM**

**KTKZ**

SACRAMENTO

*Where Your Opinion Counts™*



**Eric Hogue**

**"The Sage of Sacramento"**

**5:00am - 9:00am Weekdays**

**Wachovia Securities**

**Financial Updates with Rich Botkin**



**Paul Harvey on KTKZ!**

**News and Commentary: 5:30 AM and 8:35 AM**

**The Rest of the Story: 1 PM and 5 PM**



**Listen to the River Cats on flagship Station KTKZ:**

**Weekdays at 7:00 PM**

**Weekends Live!**



**The Salem Communications Family - KKFS/KTKZ/KFIA/KCEE/KSFS - Sacramento**