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They were the perfect family until disease claimed their son and left them with his words, 'Done — Gregory brave'

Gregory's Legacy

BY LORI EICKMANN MERCURY NEWS STAFF WRITER

"These past four years have been a journey of immense pain, and of unexpected plea - sures. Four years that we would wish on no one. Four years that we would not give up for anything in the world."

Greg Macres of Campbell offers this poignant epitaph for Gregory, his blond, bubbly 4-year-old who died from complications of a bone-marrow transplant last April. But Gregory's story is not just about sorrow.

It's also about determination, faith and — above all — love.

"The reality of life is that bad things happen," says Macres, 40, whose boyish looks and deadpan wisecracks can make you forget he has suffered the deepest pain a parent can endure. "Losing a child is really bad. We have a choice to make a positive or negative impact on our daughter, our marriage, our friends and family.

"We're going to do something positive."

The Macres family — Greg, Deborah and their 6-year-old daughter, Ashley Rose — look forward as well as back as the first anniversary of Gregory's death approaches. In the past few months, they have poured their energies into creating a foundation to research the disease that killed Gregory: Gaucher (pronounced Go-shay) Type III, a genetic disorder of the metabolism.

Through the foundation, which already has raised $30,000, and by sharing their story, the Macreses offer a forceful example of how parents can deal with a child's illness — and how love can transform.

The perfect family

After years of hard work, Greg and Deborah Macres were living the American Dream. Greg had worked his way up from odd jobs as a child in Palo Alto to a realty license at 18 to a partnership in Contempo Realty at 30. He is now senior vice president for Century 21 Contempo.

Deborah, a fifth-generation San Josean who grew up wanting to be a doctor but went into nursing because she was paying her own way, met Greg in 1984 when she was a waitress at Spoons. They married in 1988. Deborah worked as a nurse in the intensive care nursery at Kaiser-Santa Clara hospital ("It's funny how you're prepared for what life's going to bring you," she observes), and the good life kept getting better. Deborah gave birth to a daughter who inherited her mother's thick, light-brown hair, and then to a cherubic 8-pound son.

"We did feel we had the perfect family," says Deborah, 34, perched on the living room sofa and laughing when told a family friend had described the Macreses as Barbie and Ken. "We had good jobs, a great neighborhood —we were a Beaver Cleaver-type family."

Death of little boy inspires family to help others

But their dream life turned into a nightmare shortly before little Gregory's first birthday, when doctors discovered why the boy frequently vomited and wasn't growing properly. Gregory was diagnosed with Gaucher disease Type III.

Aperson who has Gaucher Type III lacks an enzyme called glucocerebrosidase that helps the body eliminate dying cells. Gregory's pediatrician, Paul Quintana of Kaiser-Santa Clara, explains that the cells, which contain abnormal compounds, remain in the body and accumulate in the liver, spleen, lungs, lymph system, bones and even the central nervous system or brain.

Gaucher appears in fewer than one in 100,000 people in the general population, according to Charlie Peters, associate professor of pediatrics in charge of blood and bone-marrow transplants at the University of Minnesota. Although, like Tay-Sachs, another "storage" disease, the incidence is higher among Jews of Eastern European descent. It also has been found in higher incidences in northern Sweden.

Gaucher tends to be more aggressive the earlier it appears. There is no cure. The Macreses, both of whom carry the recessive Gaucher gene, learned the basics of the disease between the time Quintana told them Gregory had a storage disease, and their scheduled meeting with him the next day. They researched storage diseases and recognized their baby's symptoms in the descriptions of Gaucher.

Still, the shock didn't fully hit until they returned from meeting with Quintana. "We came home and we were sitting on the couch and we were just sobbing," Deborah says. "We were just getting ready for Gregory's first birthday — now we thought it would be the last time we would celebrate it."

"A year earlier," Greg adds, "I was thinking he was going to play Little League or get a gold medal."

He pauses, then adds, "For 24 hours, we were in shock. Then we knew we needed to get information on this disease."

Jeff Culbertson, a long-time friend of the Macreses and president of Century 21 Contempo, says Deborah and Greg embarked on a relentless pursuit of information, with Web searches and plane trips across the United States.

"Losing a child is really bad. We have a choice to make a positive or negative impact on our daughter, our marriage and our family. We're going to do something positive."

The Macres, Deborah and Greg with daughter Ashley Rose on Dad's shoulders, are determined to help other families whose children battle Gaucher disease.

"Doctors were calling him for information," Culbertson says.

Those who know them say the Macreses were able to be such effective advocates for Gregory because they're intelligent, optimistic and personable — and because they could afford plane fares and babysitters needed to further their quest.

"What they did was unusual," says Kathy Kirmil-Gray, a Los Gatos psychologist who counsels the family.

"They brought their educations and their interpersonal skills to bear. They're proactive people, and they're remarkably strong people."

The Macreses don't see themselves as remarkable. When asked to describe life with a seriously ill child, Greg and Deborah say their family life was typical — even while conceding that their home was like a hospital, stocked with medical texts and medical supplies and a chart on the refrigerator to keep track of Gregory's medications.

"When you're put into a situation, you just accept what you have to do," Deborah says. Such as a real estate agent learning to medicate his son through a tube in the boy's chest.

"There are 43 steps," Greg quips, "and the 42nd one is 'Good luck!' "

When the Macreses rattle off memories of Gregory, it's like listening to a bittersweet comedy:

■ There was the time Gregory, then 2, slipped outside and went to a neighbor's house looking for a playmate. When the Macreses realized he was missing, Greg joked, "If someone has kidnapped him, I hope it's a doctor or a nurse."

■ There were the many times Gregory choked during meals. "We'd grab him and we'd be pounding on him over the kitchen sink," Deborah says, slapping at the air with her palm. "We'd look back at our guests, and they'd have this shocked look on their faces. We're like, 'Oh, I guess you're not used to this . . .' "

The Macreses laugh. Gregory, they say, was always happy, always getting up from his treatments cheerfully declaring, "Done — Gregory brave."

But there were low points. There was the time Gregory choked on grapes and turned blue and was rushed to the emergency room by ambulance; the time a quiet Sunday breakfast at a restaurant ended before the food arrived because Gregory went into a seizure; the time he was spitting up formula from his mouth while it also spewed from the tube in his stomach.

In the midst of it all, times were tense at

Contempo. The partners sold the company, and Greg became senior vice president for Century 21 Contempo. Deborah had long since quit her job to care for Gregory.

Rain is tapping on the roof as Greg and Deborah describe Gregory's last days. The medications were failing and, after more research and interviews with doctors, the Macreses decided Gregory would undergo a bone-marrow transplant at the University of Minnesota. In a pamphlet Greg wrote to tell Gregory's story and raise money for Gaucher research, he describes how Ashley, then 5, responded when asked if she would be the donor.

"On the morning before Christmas 1996, she told us, in a shuddering, frightened voice, that she was willing to give her bone marrow to her brother. Her first question was, 'When are they going to take the tubes out of Gregory's chest and put them in mine?' She had misunderstood, but her love and courage were painfully clear."

In the end, Ashley was not chosen as the donor; an unidentified man supplied the bone marrow that arrived at the University of Minnesota Medical Center in a plastic bag while Deborah snapped pictures of it and said, "Look, Gregory, this is your new life!"

Temperature soars

The transplant went smoothly, and Gregory astounded doctors by bouncing back so well that he was watching movies and eating tacos in no time. But 10 days after the operation, fever hit. "Every 15 minutes I'd take his temperature," Greg says. "It would go from normal to 101 in 15 minutes. It got up to 107."

The time came when the doctors asked Greg and Deborah to step out of the room to make way for the medical team. They agreed, but insisted they be summoned when it became clear nothing more could be done. As it happened, the last thread of life slipped from Gregory before his parents could return to his bedside. They had never been away from him before that moment.

Still, Deborah remembers the beauty in that day.

Gregory Austin Macres, almost 4, before Gaucher disease killed him.

"Greg was in a bathtub with him to lower his temperature, and Gregory held on to his neck and wouldn't let go," she says. "Later, I was in bed with him and he kept hugging my neck. He didn't usually do that. His hugging us was his goodbye."

Gregory Macres died on April 13 — Ashley's sixth birthday.

When Ashley was told that Gregory had died, she told her father that she knew it was going to happen.

"God told me," she said. "Not in my ears, in my head. He said Gregory would be in more pain after the bone-marrow transplant, so he decided to take him now."

Research fund begun

Since Gregory's death, the Macreses have been the driving force behind the Childrens Gaucher Research Fund, with a research advisory board that includes doctors from the National Institutes of Health, the University of Minnesota Medical Center, the University of Cincinnati Medical Center and Huddimge Hospital in Sweden. Their goal is to create a world-wide database of children with Gaucher Type III so that the disease can be studied and families can connect with others with the same battle.

"Families do their research, but wouldn't it be great to have other parents to talk to?" Deborah notes. "How do you get through the night? The articles don't tell you. The doctors don't know that."

As the first anniversary of Gregory's death approaches, the Macreses still are learning to be a family without him. Ashley doesn't want to share her birthday with an observance of Gregory, and her parents will honor that. They may plan something for the following day, and the family marked his birthday in January. And they remember him daily.

"I like to be with Gregory's sock," says Ashley, flashing a gap-toothed smile as her father explains that it is a small reminder that Ashley keeps.

They are the elements that keep the family going: a sock, a memory, an unfailing faith in God.

The rain has stopped. Greg clears his throat and thinks about the message he would like people to glean from Gregory's story.

"It's easy to idolize your grief," he says. "But if you idolize your grief, it becomes this negative whirlwind. I don't think Gregory looks down and wants our lives destroyed."

The “Children’s Gaucher Research Fund” is a non-profit organization, that raises funds to coordinate and support research aimed at finding a cure for Children’s Gaucher Disease (Type 2 and Type 3) as well as providing support to families who have children who battle this disease. Children’s Gaucher Disease is a progressive debilitating genetic disease which attacks children, causing a variety of systemic and neurological medical complications.
Tax deductible donations are made payable to

“Children’s Gaucher Research Fund”
P.O. Box 2123
Granite Bay, California 95746-2123.USA