

Boy's Brief Life Births New Dream for Family

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By Kara Shire, Staff Writer

DUBLIN — When Mark Wuelfing refused to eat and his little body jerked so violently that his bottle would fly across the room, his parents knew something was wrong.

Joe and Janis Wuelfing took their 5-week-old son to a pediatrician, who referred the young couple to a child neurologist. For the next two months, Mark lived in a hospital room 18 miles from his Dublin home.

Then in July, Mark died from a neurological disorder. He was 4 months old.



"Mark opened our eyes to what we have," said his mom, Janis, a teacher at Assumption School in San Leandro. "He had to go through so many things in such a short time. We want to honor him."

To do that, Joe and Janis created the Markie Foundation, a nonprofit organization that provides financial aid and support to local families of sick children.

"There's a ton of services that people who are caring for terminally ill children need," said Joe, 28. "If we can help people financially — anything that allows them to spend time with their child — that's what we're shooting for."

Janis and Joe struggled through the pressure of running a household while caring for their ailing child and their 2-year-old daughter, Madeleine.

They had support from friends, family, even strangers, who did what they could to help — oftentimes cooking dinner, mowing the lawn and doing laundry for the family.

"It was amazing," said Joe, a Web editor at PeopleSoft in Pleasanton. "We had so many people doing things for us. We are hoping we can give back a little of what we received."

The Markie Foundation made its first donation in September to a Danville couple whose infant son, Roman "Romie" Perkins, needs a bone marrow transplant.

Their \$1,600 contribution was a joint effort between the foundation and Assumption School, where a fifth-grade bake sale raised \$300.

"It was very satisfying to see that maybe we made a difference," said Janis, also 28.

A bone marrow drive is being held Saturday at the Pleasanton Hilton to help Romie Perkins and others in need of transplants. The drive, sponsored in part by the Red Cross and National Marrow Donor Program, will allow the public a free opportunity to give a blood sample that will be tested for a possible bone marrow match.

Mark Wuelfing's Feb. 21 arrival into the world was the final piece in life's puzzle for Joe and Janis.

"I've always wanted to be a mom," Janis said. "And when we had Mark, we had our daughter and we had our son, and we had our perfect family."

At first, Mark seemed fine. But his aversion to food and his frequent jerking prompted the doctor visit that changed life for the Wuelfings.

It turned out that Mark had myoclonus, a disease that arises from damage to the central nervous system. It causes a lightning-like contraction of muscles — the common hiccup is a form of this, a result of contracting diaphragm muscles.

Mark also had abnormal electroencephalogram, or EEG, results. An EEG detects electrical changes associated with epilepsy and other disorders.

Continuous seizures in his brain were causing Mark's tiny body to twitch. The misfires were happening every 30 seconds to two minutes. The disorder was causing severe neurological, development and respiratory problems for Mark. On March 25, when he was just 33 days old, Mark was admitted to Kaiser Permanente in Hayward. He would stay there for nine weeks.

Despite a "zillion" tests and consultations, doctors could not figure out the underlying cause of Mark's problems.

"We still to this day don't know what caused him to be so severely damaged," Janis said. Not knowing was hard on the couple. The two dealt with their son's medical problems in different ways — Joe sought answers, Janis realized the answers didn't matter as much as caring for their son.

Through it all, though, they stuck together.

"Our family has really jelled because of this, and we've helped each other through the uncertainty," Janis said. "As hard as it is to know you're going to lose your child, our neurologist really helped us to see Mark for who he was, and then also to appreciate our daughter for how healthy she is."

When they knew Mark's life was nearing its end, the family brought him home.

"Obviously, it was a shock," Joe said. "It was very stressful in the beginning not having answers. And after a while, it made our lives much more simple because we just had a baby to take care of."

Because he could no longer drink from a bottle, Joe and Janis fed him through a tube. He would stop breathing periodically, so they kept oxygen nearby.

Doctors told them Mark probably couldn't see or hear. It wasn't easy, said Janis, but she gave her son injections regularly and learned to resuscitate him when he stopped breathing.

"There's a lot of things as a person you think, 'I could never do those things,'" Janis said. "But as a mother who's in love with her son, you can do it."

On Friday, July 2, Mark died at his home in Dublin.

Joe and Janis are not angry.

Janis still cries now and then when she sees a baby on television, but the family is moving forward. The Markie Foundation is a way for their son's memory to move forward with them.

"He did more in his short, little 4-month life than most people do — including us — in their whole lives," Joe said. "God took care of Mark, and he's going to take care of us."

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