



A Mom With MS starts Non profit for youngest son with Very Rare disease

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On a wall above the closet in the blue bedroom, atop a wave of stars and starfish, is scrolled, "Where there is great love, Miracles happen."

Across the room, dolphins swim silently on a floor-to-ceiling mural, a stark contrast to the cavorting of "The Wiggles" bursting from the TV screen mounted on the wall. The temperature in the room is chilly, but a cocoon of warmth surrounds the little prince who lives there.

All is quiet. Today is a good day. Mom is busy elsewhere in the house, brother Noah, 10, is in his room, Dad is at work and the day nurse sits in a rocker by the window, monitoring, but enjoying the peace of the moment. In an instant the setting can change and an all-too-familiar life-saving regimen may be called into play if the myriad seizures that rack the little prince's body return.

On this day he's in a special overstuffed lounge chair on the floor, well below the hospital bed he sleeps in. Toys are scattered here and there, but his focus is on the TV screen — until a visitor walks in.

She gets the raspberries — the prince's way of saying welcome. It's a happy noise, a sign of contentment.

Welcome to Eli's world, a nucleus of monitors and magnets, medications and oxygen, feeding tubes and suction machines. It's the world of a little boy with an angelic face who, just by a fluke of nature, has a genetic abnormality so rare that fewer than 300 cases have been documented worldwide.

Elijah "Eli" Granard turns 9 on Saturday. He's survived three strokes and hundreds or maybe thousands of seizures, all related to the non-inherited condition called Ring 14, an abnormality of the 14th chromosome.

Infants and children affected typically have delays in acquiring skills to perform mental and physical activities, mental retardation, growth delays and, topping the list, uncontrolled electrical activity in the brain — seizures.

Terri and Ryan Granard moved to Newbury Park 3 1/2 years ago from San Francisco, where Eli and Noah were born.

The move brought them closer to Terri's parents, Tom and Stephanie Griffiths, who have been a major support for the family.

Terri, an LVN, is a full-time mom/caregiver. Ryan works in information technology systems for DreamWorks Animation in Glendale. Their world revolves around their sons and for five days a week, the Granard household is pretty much a fishbowl, with therapists, caregivers and others slipping paper covers on their shoes when they enter the house or donning masks to prevent germs from attacking Eli's delicate immune system.

"We have very little private time," Terri Granard admits. But on weekends the focus is on family, which could mean just staying home and Dad playing the guitar and Noah the drums. Sometimes Eli joins in, pounding on his xylophone. He loves music.

Early signs

The Granards had no clue their second son would have problems. Her pregnancy was normal, Terri said, and Eli weighed in at a healthy 7 pounds, 8 ounces.

When he was 6 months old, however, Eli suffered a stroke and seizure.

Following many hospitalizations and medical tests, including a special DNA cell test, Eli was diagnosed with Ring 14. The chromosomal abnormality, doctors said, was a "de novo" genetic mutation that neither parent possesses or transmits.

Unlike some chromosome disorders, like Down syndrome, little research has been done on Ring 14. The one major study under way is in Rome, conducted by doctors at the Children Neuropsychiatry and Genetics Ward at Santa Maria Nuova Hospital.

Stefania Azzali, whose son Matteo, is afflicted by the disorder, pushed it forward. She is president of the Ring 14 Association.

Terri, too, has become an advocate for children diagnosed with Ring 14 and other metabolic problems. She counsels parents about what to expect, resources available to them and ways to receive support.

Early on, doctors told the Granards to put Eli in a home, not to expect anything because there was not too much that could be done to help their son.

The couple didn't listen, instead nurturing hope and optimism for Eli, who has doctors at every major medical facility in the greater Los Angeles area, including Los Angeles Children's Hospital, Cedar-Sinai Medical Center and UCLA Medical Center.

The greatest spark of hope, though, comes from the Rome research project launched in 2006.

"We're hoping for a cure through stem cells or bone marrow, to figure a way to duplicate normal cells or a way for stem cells to rejuvenate," Terri said.

Research is using the child's own stem cells, not embryonic ones.

Studies are yielding trends parents can use as reference points. For example, the study notes seizures stop in boys around age 12. "Seven out of 36 boys stopped having seizures; that's what keeps us hopeful," Terri said.

The hardest part

Eli's seizures have been the most deadly manifestation of Ring 14.

"He can have one to 10 seizures a day. One Halloween, he had 80. The longest he's gone without one was four months," Terri said.

The epileptic episodes take a variety of forms — from staring into space to body tremors, major body thrashing to apneic episodes during which Eli stops breathing and needs oxygen to survive.

In years past, the Granards say they called 911 and emergency personnel responded, taking Eli to the hospital. But he often came home with infections that worsened his fragile condition. Now the Granards have a defibrillator, oxygen, medications and all the necessary tools to provide anti-convulsant therapy for Eli at home.

A couple of years ago, a vagus nerve stimulator was implanted in the youngster's chest. The VNS sends waves to the brain when needed to "interrupt" a major seizure. Its strength is enhanced with the swipe of a large magnet kept on the post of Eli's bed. The entire family and all the caregivers know the regimen, including Noah.

"Noah is 10 going on 25," Terri said, praising her oldest son. "He's amazing, a big help, the kind of kid every parent wishes he had — intelligent, mature. He's grown up in a medical house and knows about his brother's care."

Learning and learning again

Because of the strokes and seizures, Eli has had to learn and relearn various skills.

"Eli understands a lot of language, but he can't speak," Terri said. "He'll learn words and sign language and then have a seizure and have to start all over again. It's frustrating for him. He's had to relearn how to walk six to 12 times."

Currently, Eli is back to using a special walker that allows him to maneuver through the house. He prefers his bedroom, though, especially since it underwent a makeover early this summer courtesy of Tri-Counties Make A Wish Foundation. The project's inspiration was a family outing swimming with the dolphins on Maui three years ago.

Eli attends Sycamore Canyon School when he can, but his formal education is more home-based and health-driven. Speech, occupational and physical therapy sessions are ongoing. His hearing and eyesight are fine, but his body is sensitive to heat and can't regulate temperature.

During cooler weather, Eli loves being outside and going to a nearby park. Waving at people is a favorite pastime.

When he was labeled a "failure to thrive" baby, a feeding tube was surgically implanted into his stomach. While he eats some pureed foods orally, his main sustenance — including medications — is through the tube. He is now up to about 50 pounds and is 47 inches tall. He takes some 10 medications daily in addition to lots prescribed "as needed," Terri said.

Eli's 24/7 care, the medications, the therapies are all very expensive, she said. The couple's insurance pays for all but about 20 percent of the medical bills.

"It's all very expensive," Terri said. Eli's medications alone "are a couple mortgage payments a month."

'I can't ask for more'

But Eli is in no pain, he is happy and the Granards believe he has little understanding of his situation.

"He's an angel. He's happy. He enjoys his life. I can't ask for more," Terri said.

And she means it.

In 2002, while dealing with the ever-unfolding prognosis for Eli, Terri was diagnosed with multiple sclerosis. She tends to forget she has the disease.

"I don't dwell on it. I rest when I need to rest," she said. But sometimes her hands go numb and she's just plain tired.

Two years ago, another blow — she broke several vertebrae lifting Eli and underwent surgery to put rods in her back.

Terri doesn't let any of it get her down, but she does admit that, without the nurses and her parents, "I think it would have been a very different life for all of us."

Karianne Cassady, an LVN caring for Eli three days a week for 12-hour stints, puts much of the credit right back on Terri.

"Terri is a great resource person. I admire her. She's extremely calm, which keeps me calm," Cassady said.

Over the two years she's cared for him, Cassady has become one of Eli's biggest fans. "It's his sweet nature; his smile warms my heart," she said.

Terri is convinced there are many more children like her son out there, waiting to be diagnosed.

All it takes is having the right tests performed and the right medical professionals willing to dig a little deeper.

She envisions Ring 14 someday being more than just one of the "orphan" diseases, conditions so rare "they don't provide pharmaceutical companies with a profit" so they don't warrant research to find a cure.

For the Granards, every day with Eli is a blessing, including the seizures, along with the smiles and the raspberries.

"We all have something to deal with in our lifetime and you do the best you can with what you've got," Terri said. "It's just life; that's how it is."

This is Terri's story of MS.

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