

# Katie's Clinic:

## Helping families face the challenges of Rett syndrome

written BY TINKA DAVI  
 photography provided BY THE VAN GIESEN FAMILY

When Britt and Sharon Van Giesen learned on April 15, 2004 that their daughter Erika had Rett syndrome, they were overwhelmed. The diagnosis changed their lives forever.

The couple rallied around Erika, searching for ways to make her life more comfortable and to raise awareness of the disorder. In 2005, the Van Giesens launched a fundraiser, "Erika's Dream," to support Katie's Clinic for Rett Syndrome at Children's Hospital & Research Center Oakland.

Rett syndrome is a debilitating neurological disorder diagnosed almost exclusively in girls and occurring in one of every 10,000 female births in the United States. Girls appear to develop normally until 6 to 18 months of age, when they enter a period of regression, losing speech

and motor skills. Children with Rett syndrome often exhibit autistic-like behaviors, such as repetitive hand movements, prolonged toe walking, body rocking and sleep problems. There is no known cure and few treatment options.

Erika, younger sister to Megan, 15, and Brianna, 9, was born Sept. 18, 2002. "Her birth was normal," said Britt. "She was a perfect baby who never cried." However, he noticed Erika missed some 6- and 12-month "baby milestones" and began to have hand movements and delayed developments typical of Rett. Britt searched the Web and discovered Erika had 11 Rett symptoms. When a blood test confirmed Erika had Rett syndrome, Britt sat at his desk and cried.

Erika has a dazzling smile, thick curly hair and blue eyes that sparkle behind tiny bifocals. But she also displays constant

hand wringing, doesn't speak and is unable to walk. She has dramatic seizures and sometimes stays awake three nights in a row. To deal with her gastrointestinal problems and difficulty swallowing, the Van Giesens grind Erika's food, feed her by spoon and use a syringe to give her liquids and the six medications she needs.

Erika is now treated at Katie's Clinic at Children's Hospital. "The care provided to Rett families at Katie's Clinic is like no other in the world," said Britt. "The clinic, with its all-inclusive, multidisciplinary approach, is truly one of a kind. Their approach—providing outstanding care in a one-stop shop—had never been done before."

Girls receive a full day of evaluations from expert Rett physicians from fields including gastroenterology, neurology, cardiology, physical therapy, and speech and

language therapy. "That means no more driving from facility to facility to find the best doctors in their fields," added Britt.

Katie's Clinic is one of only six clinics in the United States providing comprehensive care for Rett syndrome patients, from babies to adults, and their parents. The clinic serves all the Western states, including Hawaii, and recently assessed its first international family, from the Philippines.

At Katie's Clinic, patients receive initial evaluations, as well as ongoing coordination of care and support. "It's a gold standard for Rett clinics," said Pat George, Katie's Clinic program director.

The clinic also offers consultations to schools. "The girls do academic work, learn and have memory, but they can't write or stack blocks," said Paige Nues, founding parent of Katie's Clinic. Paige and her husband, Jesse, are parents to Katie, a 6-year-old with Rett syndrome.

"Katie's diagnosis took us into a world of disability and children's health issues," said Paige. After visiting the Blue Bird Circle Rett Center in Houston and talking to other families, they saw a need for a local clinic. Children's Hospital Oakland was open to the idea, and with funds

from Erika's Dream and other donors, Katie's Clinic was founded.

Plans are underway for the next "Erika's Dream" fundraiser, set for Feb. 13, 2010. "Pediatric diseases and disorders do not disappear during a recession," said Britt. "Children's Hospital has never turned away families for inability to pay and that's why it's important to continue to give to the hospital. We need to ensure, through our fundraising, that Children's is able to uphold its high standards of service."

Dealing with Rett is not easy. "Some days we win the battle and some days we don't, and we spend a lot of time behind closed doors in tears," said Britt. "But we love Erika so much. She will always need us and will always have a special place in our life."

Thanks to the Van Giesens, the Nueses, generous donors and the success of "Erika's Dream" and other events, many Rett families will benefit from the services of Katie's Clinic and Children's Hospital Oakland.

*Tinka Davi is a Folsom, Calif.-based freelance writer and editor.*

### Other Children's Hospital fundraisers coming up include:

#### Oct. 1: 9th Annual CROSSMARK Golf Tournament

Enjoy lunch, a putting contest and 18 holes of golf on Wente Vineyard's beautiful golf course. CROSSMARK is proud to be a Children's Miracle Network sponsor. Location: The Course at Wente Vineyards, Livermore

#### Oct. 3: Swim Across America

Make waves to fight cancer. Jump into San Francisco Bay and swim 1 1/2 miles or a half-mile, from the Golden Gate Bridge to the beach at Crissy Field. Or participate in the Bay Area Pool Program. Get your team to swim 3,000 miles—the distance across the United States—and have family and friends sponsor you to support cancer research at Children's. Location: Pier 1, San Francisco

#### Oct. 27: Round Table Family Charities Golf Tournament

Join Round Table Pizza employees and friends for a day on the green to benefit Children's Hospital Oakland. You might even see the Pizza Knight tee up. Round Table Pizza is a committed Children's Miracle Network sponsor. Location: Blackhawk Country Club, Danville

#### Nov. 7: Jazzed at the Cotton Club - Gala des Enfants

Travel back in time to the 1920s New York jazz scene. The 21st annual Gala des Enfants, produced by the Rowan Branch, will be held at the Blackhawk Country Club. Enjoy live jazz music, superb food and wine, plus silent and live auctions.

For information on how to sign up for or sponsor any of our events, visit [www.chofoundation.org](http://www.chofoundation.org), email [foundation@mail.cho.org](mailto:foundation@mail.cho.org) or call 510-428-3814.

### ERIKA'S DREAM

"Erika's Dream," the major fundraiser for Katie's Clinic for Rett Syndrome at Children's Hospital Oakland, is scheduled for Feb. 13, 2010 at Artesa Winery in Napa. The gala begins at 6:30 p.m. with a silent auction and marketplace featuring 10 food vendors and 15 wineries. Dinner, a live auction and dancing begin at 8 p.m. Last year's event brought in \$135,000. For more information about attending or donating, visit [www.ErikaVanGiesenFoundation.org](http://www.ErikaVanGiesenFoundation.org).



**RETTS:** Erika's constant arm-wringing is typical of children with Rett syndrome.