

'Girl Power' Fuels Mother's Quest

by Lori Quigley

Anybody who still thinks 'Girl Power' is a term associated with action heroes or pop singers, has yet to meet Rumson native Ingrid Love Harding. Harding has turned that phrase of empowerment into her life's work to find a cure for her daughter's disability, and get unique resources for the 500,000 other girls around the world suffering from Rett syndrome.

Her organization, Girl Power 2 Cure, has helped raise more than \$400,000 – much of it \$1 at a time -- to fund Rett Syndrome research, and has provided tools, advocacy and therapy aids to families struggling with their girls' diagnosis. "Everyone always talks about 'girl power,' and I think that's great, but what are you going to do with that power?" she asks. "You can find a cure!"

Harding's daughter Sarah, 8, suffers from Rett Syndrome, the most severe and physically disabling form of autism. A potentially fatal neurological disorder that affects only girls, it has robbed her of her ability to speak, walk, or use her hands. The girls typically develop normally until about 18 months, when they begin to dramatically regress and lose skills.

Girl Power 2 Cure was formed shortly after Sarah's diagnosis four years ago as an outlet for Harding to channel all her efforts to help Sarah and girls like her, as well as give all kinds of girls a way to make a difference. Through its annual Dress Up 2 Cure Day, when children dress silly on April Fool's Day, and the sale of a CD compilation of children's music, Harding hopes she's helped researchers come a step closer to developing a cure for Rett. She's also co-founder of a start-up non-profit called the Rett Syndrome Research Trust, which has raised over \$1 million this year to directly fund scientists studying a cure for Rett syndrome.

It is estimated that a girl with Rett syndrome is born every 90 minutes -- it's as prevalent as cystic fibrosis, ALS, and Huntington's disease. The gene mutation is not hereditary, and every baby girl has an equal chance of acquiring it. Boys with the genetic mutation that causes Rett usually die shortly after they are born.



Ingrid Harding, Founder and President of Girl Power 2 Cure, with her daughter Sarah who has Rett Syndrome.

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While Sarah cannot feed herself, dress herself, walk or talk, and can only briefly hold a cup, Harding draws her strength from the joyful times to help Sarah experience as much of life as she possibly can. “We try to give her a life. It’s more than just 24-hour care. We need to make sure she’s in this world mentally, socially and spiritually. That’s why we always ask her what she thinks about things, even though we know we won’t get a response. The biggest mistake we could make would be to underestimate her.”

Maximizing Sarah’s Potential

Harding and her husband, Peter Harding, D.O., an Internal Medicine physician at Riverview Medical Center, moved the family last year from Scott Air Force Base, Illinois, to Ingrid’s childhood home in Rumson so that Harding’s parents, Doug and Peggy Love, could offer more support and companionship. The family can be seen around Rumson taking Sarah for walks outside, rides in their bicycle trailer, or walks on the beach in a special back pack. They and their other children, Gretchen, 6, and Pierce, 11, seem to have found a peaceful balance between Sarah’s needs and their everyday life. “She’s a part of everything. When we’re in the kitchen cooking, we’re helping her hold the spoon.”

Harding believes it’s this constant involvement and stimulation that helps Sarah reach her fullest potential. Just this past year Sarah has made great strides in learning to walk. She now can walk around the house just holding someone’s fingers for balance. A new walker will do wonders to increase her mobility and independence, Harding says. “When I see Sarah being brave, it helps me be brave,” Harding explains.

Not everyone touched by Rett shares Harding’s philosophy. She recalls speaking to one grandmother who said she was offended by the suggested therapeutic activities that accompanied her music CD for Rett girls. “She told me that her granddaughter could not clap her hands, and that I should suggest that they blink their eyes instead,” Harding explains. “I told her she had to help her daughter clap. Work with her, and keep those muscles moving. One of these days our girls are going to be cured, and they need to be ready!”

Searching for Answers

Harding remembers she did not always see the glass as half full. The darkest days, she recalls, were from the time Sarah started regressing, at about 10 months, until she finally had a diagnosis at 4-years-old.

“My best friends and I all had babies around the same time, and I remember watching them do things that Sarah couldn’t do yet. I tried to tell myself that Sarah was just on her own schedule, but her thumbs stayed tucked into her fists, and her toes were always curling under.”

While pediatricians and other experts kept assuring the Hardings that Sarah would be OK, the family noticed more troubling symptoms. “Finally, a friend of mine who was a pediatrician in another city asked me to look at the light reflection in her eyes to confirm if the reflection was in the same place in both. It was very different.” After a few more field tests, Harding’s friend told her “You have a problem.”

“We called in early intervention, and they sent over occupational therapists, physical therapists, speech therapists, but within a month it was like she was no longer there. She stopped looking at us. Her face just went blank. She couldn’t even hold her own head up.”

“From that point on, it was like a race to find out what was going on. I felt like if I didn’t catch it in time, if I didn’t get

What is Rett Syndrome?

- **Rett Syndrome is the most physically disabling of the autism spectrum disorders.**
- **It strikes at random in early childhood, affecting little girls almost exclusively.**
- **Many girls live into adulthood, requiring total, 24-hour-a-day care.**
- **There is no treatment beyond supportive, and often ineffective, measures such as feeding tubes, bracing, orthopedic and GI surgeries, and medications for anxiety and seizures.**
- **First recognized only 25 years ago, the prevalence of Rett Syndrome equals that of Cystic Fibrosis, Huntington’s and ALS but is vastly under funded in comparison to those disorders.**

to the right expert, it would be too late." Harding flew with Sarah from the military base in Biloxi, Mississippi, where her husband was stationed, to her parents' home in Rumson, and then to the Children's Hospital of Philadelphia. One specialist led to another. "I remember sitting on one neurologist's office and I saw a poster for Rett syndrome. I thought, I hope it's not that." But in the back of her mind, Harding suspected that it was. "Whenever I typed in her symptoms, it kept coming up."

Even so, three different tests for Rett syndrome all came up negative. At that point Sarah had yet to develop the classic Rett symptoms of hand wringing, teeth grinding and erratic breathing, so physicians could not confirm Harding's suspicions.

"One doctor even told me to stop searching. He said, 'You're going to ruin your life trying to find answer, and if you do find it you'll be devastated.'"

Then, around Sarah's fourth birthday, a contact at a Rett syndrome organization with whom Harding was communicating, called to tell her about a new Rett test being conducted in Israel. "So, we drew some of her blood and I Fed-exed it to Israel." Several months later, they learned Sarah's blood had tested positive.

By that time, Harding recalls feeling validation. "Finally, I knew she had something that other girls had too. I knew that I could learn from them, we could help each other, and that I had to get in line with them to find a cure."

Promising Research

And while that cure can't come soon enough, Harding is doing her part to make it happen. All the monies raised by Girl Power 2 Cure have gone directly to fund research.

Most recently, Harding co-founded the Rett Syndrome Research Trust (RSRT), which includes a board of advisors who are largely responsible for the major advances in Rett Syndrome research over the last decade. The most promising breakthrough to date, by an RSRT funded scientist, is the reversal of Rett syndrome in a mouse model. The RSRT's goal is to reverse Rett in humans.

And, because the gene involved in Rett syndrome is also implicated in many other neuropsychiatric conditions, it is believed that Rett research will also advance research into Parkinson's disease, autism, schizophrenia, bipolar disorder and Alzheimer's. "Some call it a Rosetta Stone," Harding explains.

The RSRT's goal is to start clinical trials for new treatments within five years, or in more personal terms, before Sarah turns 12. Those studies that appear to be the most readily translatable into treatments are being pursued simultaneously, and according to RSRT statements, the Trust will quickly prioritize resources as new information emerges.

It's clear Harding's eye is always looking toward a cure, but Sarah keeps her and her family grounded in the moment. "She has taught us all to feel empathy and patience, and to appreciate all we have.

There are a lot of times I look at her and think, she couldn't be any happier at this moment, even if she could walk and talk. When we're wrestling and tickling as a family, when we're swinging in the hammock, when the dog is licking her face, she just laughs out loud. It's pure joy. I latch onto those moments."

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LINKS:

Girl Power 2 Cure - www.girlpower2cure.org

Dress Up 2 Cure - www.dressup2cure.org

Rett Syndrome Research Trust - www.rsrt.org