



ABOUT TFG
CONTACT TFG
FREE TFG
ADVERTISE TFG
SHOP TFG

THE
FAMILYGROOVE
GET IT™

HOME
LIFESTYLE & HOME | FASHION & BEAUTY | WELL-BEING & HEALTH | BUMP WAT

CHARITY OF THE MONTH

JANUARY 08

Get more
CHARITY OF THE MONTH



GIRLS INTERRUPTED

WHAT IF YOUR INFANT DAUGHTER AT AROUND 10 TO 18 MONTHS OLD WAS ROBBED OF THE ABILITY TO TALK, WALK, USE HER HANDS OR MOVE AROUND NORMALLY? WHAT IF HER AFFLICTION COULD BE CURED? WHAT WOULD YOU DO TO SAVE HER?

What is
Rett Syndrome?

The most severe form
of **AUTISM** that
only affects **GIRLS!**

Every day another 20 little girls are born with Rett Syndrome...close to half a million girls have been robbed of their speech and ability to walk or use their hands.

Rett Syndrome is the leading cause of severe impairment in females.

Every five hours another girl is born with Rett Syndrome. As prevalent as Lou Gehrig's disease or Amyotrophic lateral sclerosis (ALS), cystic fibrosis and Huntington's disease, Rett Syndrome is the leading cause of severe neurological impairment in females. The syndrome, created by a random gene mutation is classified as the most severe form of autism that could afflict any baby girl. It causes uncontrollable seizures, gastrointestinal pain, scoliosis and even sudden death.

"We started being suspicious that something was wrong with our daughter, Sarah, when she was around six months of age. Sarah still tucked her thumbs into her palms and could not hold her head up very well. At 10 months, she lost the ability to hold her bottle, babble, smile and crawl. We thought she was dying and frantically tried to figure out what was wrong. We feared that we would find out too late and lose her. We flew her to Children's Hospital of Pennsylvania (we were living in Mississippi at the time courtesy of the Air Force), but no one could figure out what was happening. It's weird—there was a poster about Rett Syndrome hanging on the wall and I remember reading it and thinking, "Oh my God, I hope she doesn't have that," says Ingrid Harding, founder of Girl Power 2 Cure, a non-profit dedicated to raising funds for treatments and a cure for Rett Syndrome.



Sarah and Ingrid

After a first test result for the syndrome came back normal, it took the Hardings three more years to realize what was happening to their daughter. It wasn't until Sarah was four years old that a more comprehensive test showed her to indeed be suffering from Rett Syndrome.

Harding says that life with her daughter is bittersweet. "She is six years old now, so it's getting more and more difficult to hold back the tears when we see the other kids her age doing things so effortlessly. She is so brave, though. Imagine the frustration of not being able to communicate. She depends on us for every part of her day: feeding, diapering—the works. We usually carry her from place to place in the house, although sometimes she will walk with us holding her up under the arms. She has a great smile and an infectious giggle—and I wouldn't trade them for walking. She has taught me so much. She definitely taught me about patience and that there is a beautiful soul inside every human being, regardless of outward appearance and capability. She has taught me to persevere and fight and that every day is a new day with a new chances and new possibilities," Harding tell us.

Harding started Girl Power 2 Cure in May 2006 in hopes of bringing mainstream awareness of Rett Syndrome to the public, while helping to the raise money it will take to cure Sarah and girls like her.

"We are all about harnessing the spirit of girls as volunteers, mentors and a power of positive change in their communities in support of their fellow girlfriends who are suffering from Rett Syndrome," says Harding, who also created a *Girl Power* CD as a source of revenue for the cause and as a gift for the girls themselves because "Sarah has always responded amazingly to music. She does so much more when music is playing. I had to share this discovery with the other girls out there in hopes that it has a positive effect on them, too."

The organization endeavors to get a CD, which also features therapy activities that go with each song, out to every family with a daughter suffering from Rett Syndrome and to brand the Girl Power flower icon as a nationally recognized symbol (think breast cancer's signature pink ribbon). "A girl who wears the flower will be telling the world she has helped a girl with Rett Syndrome and is part of a movement to cure a disorder that is afflicting her fellow girlfriends," Harding says.

When asked what advise she has for other parents with daughters suffering from the syndrome, Harding says, "Stay strong. Believe in your daughter. Talk with her, dream with her, kiss her goodnight. Have the highest aspirations for her. She will bring people together like only an angel could do. She teaches through her silence and her pain. She reminds all of us how best to live our lives. Fight for her. She will be able to tell you how it all felt one day."

Harding speaks from optimism and education. In fact, Rett Syndrome was proven reversible this February. "We know we can get our girls back. Hundreds of thousands of them are waiting for us," Harding adds.

What can you do to help?



Personalized Candy Bars

Party Favors & Birth Announcements



Facts & Photos
Wrapped around Hershey's Bars & more!
FOR ALL OCCASIONS
(Shipped Quick)

www.babygrams.com 800 459-9859

[HOME](#) | [ABOUT TFG](#) | [CONTACT TFG](#) | [FREE TFG](#) | [ADVERTISE TFG](#) | [SHOP TFG](#) | [PRIVACY POLICY](#) | [TERMS & CONDITIONS](#)