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If you're curious what hope looks like, just look into the eyes of Juliana Brooks. She's a 5-year-old girl who's smart and beautiful. She has so much to say but can't say it ... yet. After developing normally for the first year of her life, she was diagnosed at 2 ½ with Rett Syndrome, a neurological disorder typically found in girls that affects her ability to walk and talk. She and her family – mom Kristy, dad Roger and sister Olivia, 3 – live in Irving, enjoying each day as they await a cure.

HOW WAS JULIANA DIAGNOSED?

When she was born, everything was perfect. She was always happy. At nine months she was bab-

bling and crawling. Life was great. She started to miss a few milestones, but the pediatrician told us it's OK – some children are slower to develop. We waited a few months longer, and when she was a year old, it felt like overnight she stopped talking, stopped crawling. We went to a neurologist and got a very discouraging report. We asked what we could expect, and he said on a good note, she may be able to sack groceries; on a bad note, you'll be taking care of her for the rest of your lives. We were sent to a geneticist to test for Rett Syndrome, and when we got the positive results we were just shocked. The ground went out from beneath us. We went through a depressive state for a

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while, but that is when we found Girl Power 2 Cure. We have a lot to be hopeful for; they've been able to reverse this condition in mice, so a cure is possible. She has a local neurologist and also works with Dr. Sasha Djukic, the director of the Rett Syndrome Center at The Children's Hospital at Montefiore in New York. Meeting with her changed our lives. She gave us new tools for communication. We were really at a loss for how to communicate with her, and she introduced us to the Eye Gaze computer that Juliana controls with her eyes to speak.

WHAT IS YOUR INVOLVEMENT WITH GIRL POWER 2 CURE?

Girl Power 2 Cure (girlpower2cure.org) was our savior at a time when we were really down and uncertain with what to do. They are all going through the same thing we are. Roger serves as the chairman of

ABOVE / The Brooks family in their back yard: mom Kristy, dad Roger, and kids Olivia, 3, and Juliana, 5.

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the mom next door

the board, and I serve on the mom advisory board. The mission of Girl Power is raising awareness and funds for Rett Syndrome research. Our big fundraiser is a golf tournament on April 21 at the Indian Creek Golf Club in Carrollton.

HARDEST PART OF THE JOURNEY? Initially looking at what the future was going to look like was very, very difficult. We had to learn to look at the progress she makes. Now she's thriving and she's 5, but it's really hard because she's starting to understand her limitations. She's a typical 5-year-old girl, except her body doesn't do what she wants it to do.

PROUD MOM MOMENT? I got a note from Juliana's teacher that said, "Everything I asked Juliana to do, she said no. She refused to participate." I put on my serious face and told Juliana that is not OK – we're going to look on your computer and find "I'm sorry," and when you get to school tomorrow, you say you're sorry to your teacher, and she said yes. So I wrote in her notebook to her teacher, "When you open Juliana's computer, she has something to say to you." So her teacher wrote back, "I turned on her computer, but I was really confused because all she kept saying was, 'I was just kidding.'" That little stinker didn't want to say her sorry. We were excited she did something a typical 5-year-old would do.

WHAT IS HER RELATIONSHIP LIKE WITH HER LITTLE SISTER? It's beautiful. Olivia sees nothing wrong with her. Juliana is her big sister, and she wants to do everything Juliana does. It's still difficult when people ask what's wrong, and it breaks your heart to have to explain every time. One morning, one of Olivia's friends asked, "Well, if she's 5, why doesn't she talk?" I immediately froze and thought, what do I say, what do I say? And Olivia, without missing a beat, said, "Yes, she does talk. If you ask questions like, 'Juliana, do you want juice?' and if she says yes, she turns her face like this, and if she says no, she goes like this, and she has a computer and can pick all kinds of things to say. She can talk." I thought, this 3-year-old child explained it so easily. I've stolen her answer several times when people ask.

HOW DO YOU HELP OLIVIA UNDERSTAND HER SISTER'S CONDITION? We haven't really had to explain it. She's grown up with her. She sees the things we do for her, and she wants to do the same. If we go outside and I put their juices out, she gets Juliana her juice first. She's very helpful and knows no different.

WHAT IS JULIANA'S PERSONALITY LIKE? She is a fighter. She never complains; she's very patient. She's hilarious – she can make you laugh, she has the most contagious giggle.

I CAN TELL YOU AND ROGER ARE A GREAT TEAM. TALK ABOUT HOW YOUR MARRIAGE HELPS YOU THROUGH THIS CHALLENGE. I don't know that I could do it without him. We complement each other. Juliana loves her daddy; she's a daddy's girl. It's a four-way partnership. Everyone in this family does their share, and it's not a job to us.

ONE THING YOU'RE THANKFUL FOR ... I'm very grateful for her doctors and the people conducting this amazing research to find a cure. This condition may very well be the first neurological condition that is completely curable and reversible. The wonderful thing is, her brain is completely intact, it's not degenerative and she's not getting worse, so whether this cure comes tomorrow or in five years, she's going to be cured. 