

About the Ella Foard Foundation:

We had all the right milestones: her first crawl, her first word, her first step, but soon things slowly began changing. Ella would prefer to stand alone and rock back-and -forth for hours while her sister and cousins played right beside her. Ella didn't say the typical 2-3 toddler phrases, but instead would revert to nonverbal cues to communicate. Regardless of how fast we would spin Ella in our arms, she didn't hold on tight.

As with most parents, when these small things happen, they were rationalized away. But these moments became habits and that's when we stopped to find out what was happening to our daughter. It was a journey that involved months of not knowing and endless speculation. It was an introduction to disorders I never wanted to know about and therapies that could help. We were determined as a family that Ella could get through this "delay." On a doctor's chart, I was introduced to Rett Syndrome. After doing what we all say we won't do, I started Googling more information. The search came back with: *Rett Syndrome (RTT) a unique neurodevelopmental disorder which begins to show its affects in infancy or early childhood, affecting almost exclusively females. RTT is a rare genetic disorder of developmental arrest or failure of brain maturation that is found in all racial and ethnic groups throughout the world.* Deep down, I knew this was Ella's diagnosis even though I didn't verbalize it. After months of doctor's visits and testing, it was confirmed on 1/10/08 —Ella is a Rett girl.

The devastation and boldness of the news was felt by all of us. We thought of all the other milestones that Ella would not have and the "normal" life that was taken from her. But with most parents, we had to make a decision in that moment—to be there for our daughter. As much as we wanted to dwell in anger and sorrow of this news, we couldn't— we had to find the hope, the strength, and the resiliency to start another day and be parents to our girls. Now, we try to celebrate the smaller milestones we have with Ella like when she learns a new word or has a great day in physical therapy.

As a family, we accept Ella for who she is, a feisty, gentle, funny child, and what she brings to our lives.

The reason we are writing this is to share our perspective and to give everyone an opportunity to know its okay to ask questions. Questions will help us get to answers. Many people ask if there is anything they can do and our response is an astounding **Yes!** Whether it is donating the price of your weekly lattes or writing your local representative for more funding, every little bit helps to bring awareness and hope for a cure.

Armed with our commitment, passion, and determination to provide the best life for our daughter Ella we knew we had to do something to increase awareness and raise funds for a cure. Along with the requests of friends and family to get

involved we decided to take our efforts to the next level, and with that.....The Ella Foard Foundation for Rett Syndrome was founded. Please come along and be a part of our journey.