

Not an “Error” But Our Child

BY Laura Echedvarria

Sarah Hanson is an adorable nine-year-old. Looking at her photo, you immediately notice her strawberry blond hair, her blue eyes, and her ready smile. She recently was named Student of the Week at school. Her teacher wrote, “Sarah demonstrates the six pillars of honesty every day. She is honest, kind and compassionate. She plays by the rules and always perseveres, trying to do her best. Sarah is very enjoyable to have in our class.”

You may have noticed from her photo that Sarah has Down syndrome. Some children with Down’s are more susceptible than other children to certain conditions and diseases. While the winsome photo of a cute and happy Sarah gives little evidence of the struggles her body has gone through, her facial expression tells us she is loved and adored by her parents.

When Brenda was seven months pregnant, she and her husband Mark were told that something was “wrong.” Their daughter had Down syndrome. Brenda says that her doctor never mentioned abortion but she and her husband would never have considered ending their unborn child’s life.

Since her birth, it seems as if Sarah has suffered from every disease or condition her Down syndrome makes more likely to occur. For instance, when she was 20 months old, Sarah’s young body was ravaged by a series of strokes that left her a quadriplegic.

Moyamoya syndrome, the condition that caused the strokes, is an extremely rare genetic condition that occurs more commonly in children with Down’s. Sarah subsequently had to have lifesaving brain surgery to route new blood vessels and provide her brain with a better and more reliable supply of blood.

Likewise, leukemia is often more common in children with Down syndrome than with children in the general population. Sarah has suffered from this disease but is in her second year of remission.

While Brenda and Mark have had more than their fair share of troubles, Brenda has an amazingly positive response to helping Sarah deal with her disabilities and conditions. Brenda views them as opportunities to become better parents and better people.

She is unstinting when she writes about Sarah’s medical conditions. Sarah, Brenda writes, has “Down syndrome and hydrocephalus. And a heart defect. And a vascular disorder that led to some serious strokes which led to spasticity and the inability to perform any activity independently. And a feeding tube. And diapers for the rest of her life. And acute lymphocytic leukemia.”

But, at the same time, “I [have] never, ever, ever thought of Sarah as an ‘error.’ ... Children with Down syndrome, just like normally developing children, have the potential for experiencing life. There is purpose in that. They have the potential for teaching us the joys of ‘small’ successes. They remind us to be thankful for our health and life and capabilities—because each of us, really, is just one car wreck away from being disabled ourselves. [Children with Down syndrome] offer us the chance (in C.S. Lewis’ words) of ‘becoming heroes.’”

It's not that Brenda and her husband haven't struggled, or that Sarah's diseases and conditions haven't taken a physical, mental, emotional, and spiritual toll. But, as parents, Brenda and Mark have taken the opportunity to experience Sarah's life as a blessing—however long Sarah may be with them.

Sarah is a happy little girl who strives to do her best. In turn, she has brought out the best in those around her.

One example is Sarah's 10-year-old cousin Emily. Emily was assigned to write a paragraph at school about a Christmas wish. She wrote:

"If I could give one wish to someone it would be my cousin Sarah. I wish that doctors could find all of the cures for Sarah's many diseases. One reason I would wish for this is so she wouldn't have to go to the hospital. She has to go for a lot of transfusions. Sarah has multiple diseases and disabilities. I wish that I could find a cure for her leukemia also!! I would do this because that is her biggest complication and most serious she is facing right now. Sarah has a lot of complications and that is why I wished doctors could find a cure for them!!"

Sarah's young life, no matter how difficult, no matter how long, has been full and has had meaning. Brenda writes, "Sarah's Down syndrome and other medical struggles have meaningful purpose that I, as a parent, am responsible for helping her discover and then sharing with the world."

Would that the world would listen and learn.