

# no child is perfect. every child is perfect.



**I**T HAS BEEN EIGHT-and-a-half years since I looked into my newborn daughter's eyes and thanked God for giving me a perfect child.

It has been seven years since Schuyler's pediatrician first asked if she was making any attempts to speak.

It has been five years since the fateful day Schuyler's pediatrician and a neurologist told us about the monster living in Schuyler's head, a rare brain malformation called *polymicrogyria*. They explained what effects this monster would have on our baby girl - about the seizures she might have, the possible swallowing disorders, the risk of mental retardation, and, most of all, the spoken words that never would come.

It has been five years since I offered up the only prayer I ever truly sent to God - to take Schuyler's affliction away from her and give it to me, to take my

voice and give her the one she lacked. God didn't do this, of course, so it has probably been five years since I also lost my faith.

The idea of a "perfect child" is both a little shameful and inevitable, no matter who you are or what obstacles and triumphs you face as a parent. Most of us say we will accept and be proud of our child no matter what, and we mean it. Yet, I can't imagine there's one of us who doesn't carry a secret narrative in our heads - our little valedictorian or Nobel prize winner, thanking us from the podium. We carry hope for our kids, for them to achieve more than we did, and, by extension, carry our lives beyond our years.

Life with any child is a drawn-out process of painfully and incrementally letting go of this perfect child narrative. Yet, it's more acute when your child develops into one that is, for whatever

reason, "different." For the parent of a child newly diagnosed with a disability, that disengagement is sudden, and the pain is sharp. It is nothing less than a grieving process, mourning the loss of a child who never existed and most likely was unrealistic all along, but who nevertheless is missed as surely as if he or she had lived and died.

What we are left with is a child who exists, with all her flaws and differences, as a total and complete and complex human being. The idea of "perfect" is doomed to begin with, depending as it does on our subjective ideas of what constitutes a flaw. Our children are who they are, and what we might forget (but absolutely should not, ever) is that the measure of their quality is not in their flaws, but rather in how they confront them. Children with disabilities do this in ways that are grand and obvious, and we, their parents, celebrate them largely and proudly. Some of us even write books about them.

But, every child works to overcome differences and fears and even our unreasonable expectations. It is in that work, and in the exercising of their character made strong like muscles, that our children grow. It is in that way that they ultimately become perfect - not because they aren't flawed, but because they are. They are flawed, and they are loved, and they are becoming people who will one day astound us, if only we give them the chance.

It has been eight-and-a-half years since Schuyler began her journey toward perfection. Like the rest of us, she'll never achieve it. Yet, in all the ways that count, she is already there. *Robert Rummel-Hudson is the author of "Schuyler's Monster - A Father's Journey with His Wordless Daughter."* See our Book Reviews for further information. ★