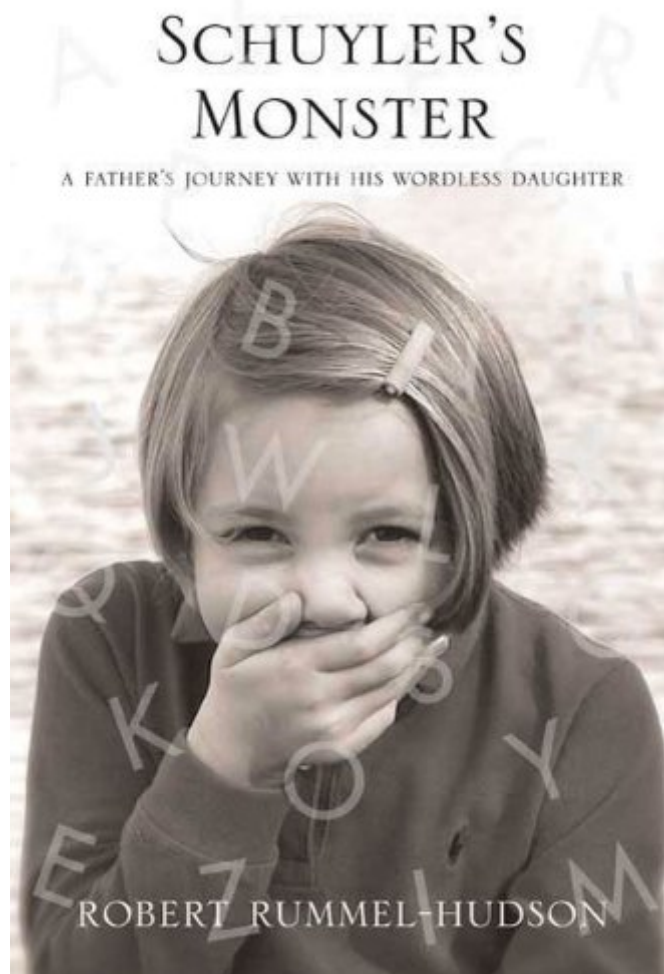


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Schuyler's Monster: A Father's Journey With His Wordless Daughter



Synopsis

Schuyler's Monster is an honest, funny, and heart-wrenching story of a family, and particularly a little girl, who won't give up when faced with a monster that steals her voice but can't crush her spirit. When Schuyler was 18 months old, a question about her lack of speech by her pediatrician set in motion a journey that continues today. When she was diagnosed with Bilateral perisylvian polymicrogyria (an extremely rare neurological disorder caused by a malformation of the brain.), her parents were given a name for the monster that had been stalking them from doctor visit to doctor visit and throughout the search for the correct answer to Schuyler's mystery. Once they knew why she couldn't speak, they needed to determine how to help her learn. They didn't know that Schuyler was going to teach them a thing or two about fearlessness, tenacity, and joy. Schuyler's Monster is more than the memoir of a parent dealing with a child's disability. It is the story of the relationship between a unique and ethereal little girl floating through the world without words, and her earthbound father who struggles with whether or not he is the right dad for the job. It is the story of a family seeking answers to a child's dilemma, but it is also a chronicle of their unique relationships, formed without traditional language against the expectations of a doubting world. It is a story that has equal measure of laughter and tears. Ultimately, it is the tale of a little girl who silently teaches a man filled with self-doubt how to be the father she needs. Schuyler can now communicate through assistive technology, and continues to be the source of her father's inspiration, literary and otherwise.

Book Information

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Customer Reviews

In Schuyler's Monster, Robert Rummel-Hudson tells a story of coming to terms with, while constantly battling, what he calls his daughter's "monster," a disease called polymicrogyria which leaves her unable to talk. She can make some sounds, using mostly vowels, and it's not until age 4 that the author and his wife even find out precisely what is wrong with her. In this incredibly heartfelt memoir, Rummel-Hudson recounts their journey from parents to "special needs" parents, navigating school systems in Connecticut and Texas in their quest to get Schuyler the best care and help she can provide. At times, their story is bleak, but throughout it, Rummel-Hudson's overwhelming love for his daughter, as well as his belief in her, is clear. Even when things seem at their worst, the couple never let their daughter sense their doubts about her being "broken," as Rummel-Hudson writes. Even though he uses this terminology for her and her brain, on a certain level, he seems to know that for whatever mysterious reasons (his battles with faith and a god he doesn't quite believe in are covered in the book), Schuyler has turned out the way she has. Some of the best moments are focused solely on Schuyler. She is a "rock star" amongst her young classmates, in various schools, looking the part with purple or red hair and pink leopard print, and drawing her peers around her. When she stands up to (and punches) a bully at a mall playground who's just shoved her and teased her for being a "retard," it's hard for even those of us who are as nonviolent as they come to cheer.

Schuyler's Monster is not some phantom conjured by a child and reported to live in her closet. Her Monster is real, a genetic abhorration, residing in the very structure of her brain tissue, invisible to all save the MRI machine. The monster is invisible; Schuyler is silent. I was very excited to read this book, as I too have a wordless daughter. In the beginning I was disappointed because it felt like it was Robert's autobiography and not Schuyler's story, and to some extent that feeling carried through for the first half of the book. As I pondered the book after finishing it a couple of thoughts combined to bring this book up from a three star rating to a five. First, I thought a lot about my impatience with the author telling his story. As the parent of a severely handicapped child, I wasn't interested in the father's frustrations and emotional roller coaster. If I am completely honest, I felt

just a bit of exasperation with him for not focusing on all the things that his daughter could do. As opposed to, say, my daughter. However, as I mulled things over, several things became clear to me. The average reader does not have a daughter like his Schuyler or my Winter, and would, therefore, have no idea that a train wreck in slow motion is a pretty good metaphor for how your life, as the parent, can feel as you try to keep your child on the track. And the more I read about Robert the more I realized how eloquently he managed to express, without ever losing his sense of humor or poignancy, how one survives this kind of a life altering challenge. I identified so completely with his struggle, and that proves what a beautiful job he did in conveying the reality of our lives to someone who doesn't live it every day.

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