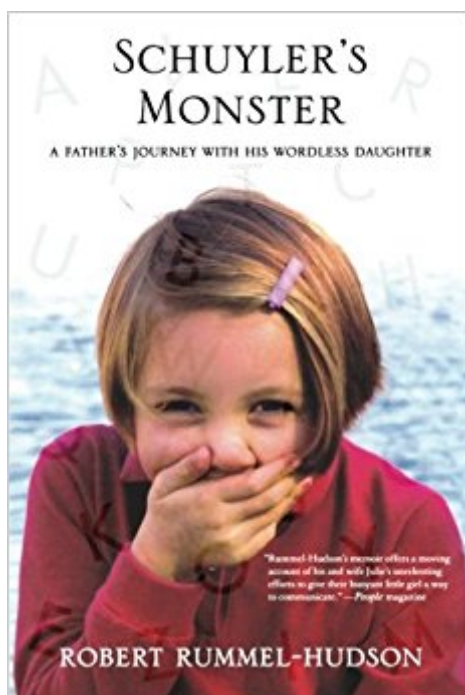


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# Schuyler's Monster: A Father's Journey With His Wordless Daughter



## Synopsis

When Schuyler Rummel-Hudson was eighteen 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), her parents were given a name for the monster that had been stalking them from doctor to doctor, and from despair to hope, and back again. Once they knew why Schuyler couldn't speak, they needed to determine how to help her learn. They took on educators and society to give their beautiful daughter a voice, and in the process learned a thing or two about fearlessness, tenacity, and joy. More than a memoir of a parent dealing with his child's disability, Schuyler's Monster is a tale of a little girl who silently teaches a man filled with self-doubt how to be the father she needs.

## Book Information

Paperback: 288 pages

Publisher: St. Martin's Griffin; Reprint edition (January 6, 2009)

Language: English

ISBN-10: 0312538804

ISBN-13: 978-0312538804

Product Dimensions: 5.5 x 0.6 x 8.5 inches

Shipping Weight: 15 ounces (View shipping rates and policies)

Average Customer Review: 4.6 out of 5 stars 57 customer reviews

Best Sellers Rank: #96,566 in Books (See Top 100 in Books) #93 in [Books > Parenting & Relationships > Family Relationships > Fatherhood](#) #94 in [Books > Biographies & Memoirs > Specific Groups > Special Needs](#) #104 in [Books > Parenting & Relationships > Parenting > Parenting Girls](#)

## Customer Reviews

The monster in this heartfelt memoir is polymicrogyria, an extremely rare brain malformation that, in the case of Rummel-Hudson's daughter Schuyler, has completely impaired her ability to speak. During her first three years, as her parents seek to find out what hidden monster is causing her wordlessness, they endure two years of questions and tests and at least one unsatisfactory diagnosis. But while Rummel-Hudson initially rages at God for giving Schuyler a life that would never ever be what we'd imagined it to be, his depiction of her next four years becomes a study not only in Schuyler's vivacious and resilient personality, but also in the redeeming power of understanding and a stupid blind father's love. As he describes how Schuyler eagerly takes to

various forms of communication, such as basic sign language and an alternative and augmentative communication device that provides whole words she can type to express her thoughts, Rummel-Hudson effectively and compassionately shows how the gentle strangeness about her, like a visitor from some realm where no one spoke but everyone laughed, leads him to understand that she was the one teaching me how to make my way in this new world. (Feb.) Copyright © Reed Business Information, a division of Reed Elsevier Inc. All rights reserved. --This text refers to an out of print or unavailable edition of this title.

“A gripping explication, shot through with equal parts horror and hope, of how parenthood can turn ordinary people into passionate advocates.” Neal Pollack, author of *Alternadad*

“Robert Rummel-Hudson is brave enough to reveal the damage the discovery of his child’s condition did to his marriage and to his own sense of self. He manages to repair some of the damage through close involvement with Schuyler and vigorous campaigning on her behalf. His memoir is honest, often painful and deeply personal.” Charlotte Moore, author of *George & Sam*

“The book is engaging and honest - I’m sure it will help many parents who are struggling to find the most loving way to help their children who have ‘issues’.”

Dana Buchman, designer, author of *A Special Education: One Family’s Journey Through the Maze of Learning Disabilities*

“Rummel-Hudson’s memoir offers a moving account of his and wife Julie’s unrelenting efforts to give their buoyant little girl a way to communicate.”

People magazine

“Relating the battle for his exceptional daughter with nimble wit, ardor and considerable descriptive ability, Rummel-Hudson has evolved from blogger to author.” Kirkus

“A study not only in Schuyler’s vivacious and resilient personality, but also in the redeeming power of understanding.”

Publishers Weekly

“This memoir, full of fear and rage and disappointment and acceptance and advocacy and ferocious love, offers plenty of touchstones for parents who have dealt with diagnoses that are infuriatingly wrong or frighteningly right.”

Terri Mauro, author of *The Everything Parent’s Guide to Sensory Integration Disorder*

“Rummel-Hudson chronicles, with disarming frankness, the experience of parenting a child no one knows how to help.”

Brain, Child

“This story will both compel and inspire readers on their own self-journey.”

Texas Family magazine

“We all play the hand that we are dealt in life. Knowing that there are many people like Robert, Julie and Schuyler who play their difficult hand with grit, tenacity and love makes this world a much better place in which to live.”

The Citizen, Auburn, New York

Many years ago I stumble upon a "blog" by this author while searching for something about the spelling of Rachmaninoff. His columns were a delightful surprise, even the ones that made me cry. I can say the same for this memoir. My only disappointment is that I only recently found it (two e-mail and one state move for retirement later) so it doesn't bring me up to date on the journey of this family. However, and again another stumble, Mr. Rummel-Hudson has a Facebook presence so I'll leave future readers to enjoy this story and seek out the continuation of this family on their own. So well written and poignant without ever becoming maudlin. I do hope the gifted Robert Rummel-Hudson will be able to write another book in my lifetime.

This is a story of loving (and all too human) parents, and an extraordinary child. Rarely do you find a child who has special need described with such humor. There is always love, just as there was in this story, but humor and honesty and passion have equal roles. I work with children who have special needs. Even though none of them have the same diagnosis as Schuyler, some of the obstacles they face are the same. The most difficult, is always communication. It is what the parents want the most, the children need badly and what is all too often not given enough attention. This is a story of Schuyler's life, from conception to present day, more or less. The reader learns all about the world she developed in and how she began to grow. We learn what Mom and Dad are like, and how they learned along with their daughter what she needed to be happy and purposeful. I wish that more of the parents had the gumption of these two, instead of sitting in IEPs and just going with the flow. I wish that more use was made of these communication devices, and not just 10 or 20 minutes during the day. I would like to give a copy of this book to every single family in our school. ( Things would really start hitting the fan, then!) Well done Schuyler's daddy...! Good job Schuyler's mom. Keep up the good work, because I am sure that there will be more beneficiaries from it than just your amazing little girl. I highly recommend this book to anyone who has a child, and anyone who does not. I particularly recommend this book to anyone who works with or runs schools for special needs children...or typical children. You are the ones who need to learn to reach for the stars.

I found this book in the Black Oak bookstore on a recent day trip to Berkeley with my youngest daughter (the one who was never 100% neurotypical), and it's turned out to be the best possible souvenir of a wonderful day. Unfortunately, thanks to Robert Rummel-Hudson and his improbably funny, engaging style (how many books about neurological disorders and fights with special education administrators can lay claim to having many laugh-out-loud moments??), I've gotten no

housework, homework, cooking, cleaning or other reading done in the three days since I acquired the book--and I got a lot of funny looks from the other parents at the neighborhood water park today, as I sat, happily oblivious to the periodic spray of water cannons, laughing wildly like Schuyler over my book while my kids played nearby. Thank goodness the author keeps a blog, so now that I've finished the book I don't really have to say a final goodbye to him or to Schuyler--I can just keep tabs on them periodically, and make sure they're doing okay and continuing to thrive in Plano.

great book. eye opening

Heartbreaking but beautiful; an excellently written account of an imperfect but lionhearted father and his incredibly lovely, spunky, wordless daughter, as well as those who have supported them throughout the difficult journey of discovery, diagnosis, and determination to embrace life on their own terms.

I loved how the author was open to sharing his feelings as they went through the long diagnosis process, knowing it just wasn't right, at first. He seemed to advocate for his daughter, but also be realistic in her abilities. Parts of this book made me so sad, and other parts so angry. Very inspiring read to this parent/speech pathologist.

I was instantly intrigued by this title as a pediatric SLP. Rummel-Hudson was honest about the frustrations I'm sure many of our parents feel going through the system, yet he did it in a way that didn't immediately put me on the defensive. Perhaps I felt beleaguered in getting through it because of my profession or perhaps it was the quality of the writing, but I felt that the pace of the book was very, very slow to get through. I found that I read it in chunks spread apart by months rather than in one short time frame. It is one of the most real depictions of the unknowns families face in the first 3-6 years of raising a child with special needs I've seen, but is also unnecessarily delves into other aspects of the author's life that, while likely important to his personal journey, didn't interest me the reader.

Rob is honest and unapologetic when writing Schuyler's story. It's not always easy to see the hurt and challenges will be outweighed by the triumphs and joy of Schuyler finding her way in a world not always designed for her. What a raw and real depiction of life with a special needs child!

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