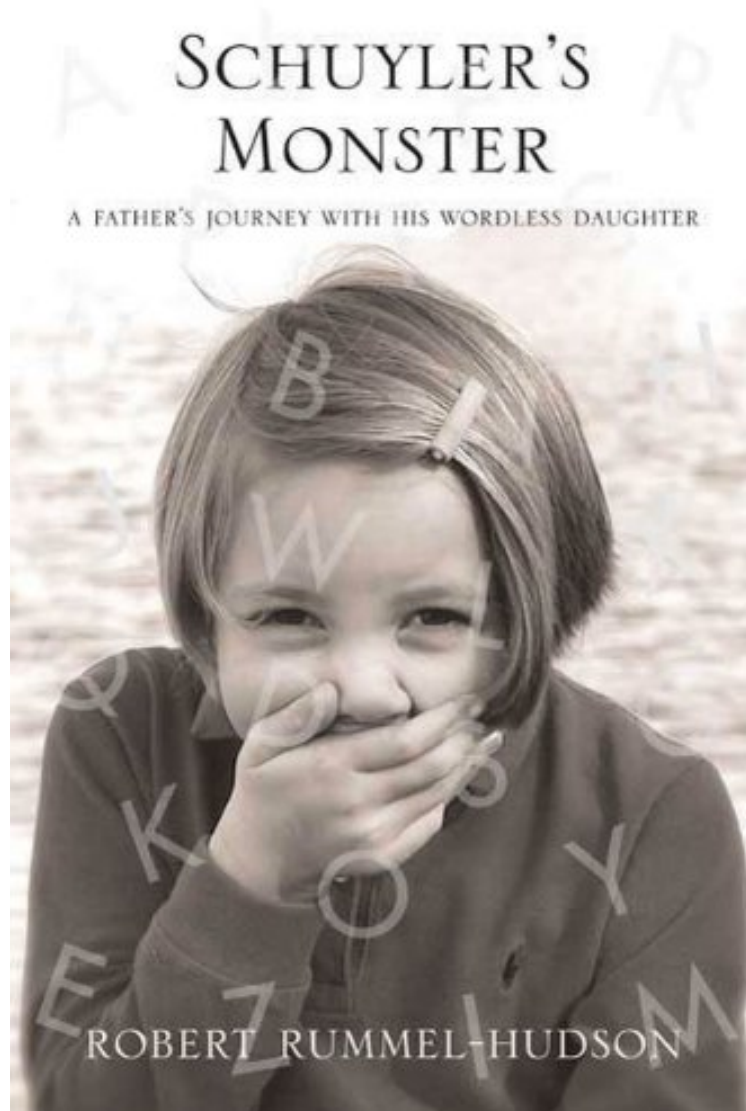


(Library ebook) Schuyler's Monster: A Father's Journey with His Wordless Daughter

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

Von Robert Rummel-Hudson

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Von Robert Rummel-Hudson : Schuyler's Monster: A Father's Journey with His Wordless Daughter before purchasing it in order to gage whether or not it would be worth my time, and all praised Schuyler's Monster: A Father's Journey with His Wordless Daughter:

KundenrezensionenHilfreichste Kundenrezensionen3 von 3 Kunden fanden die folgende Rezension hilfreich. Geniales Buch!Von Little SpecterDas Buch hat mich unglaublich beeindruckt. Keine noch so gut erfundene Geschichte ist

spannender als das reale Leben. Schuyler, die Tochter vom Autor, hat eine seltene Krankheit, die u.A. bewirkt, da sie nicht wirklich sprechen kann. Dadurch, da die Krankheit so selten ist, dauert es lange, bis die Krankheit überhaupt diagnostiziert ist, und noch viel länger, bis die Familie auf Sonderschullehrer trifft, die in der Förderung des Mädchens tatsächlich Ahnung von dem haben, was sie tun. Schuyler ist ein sehr lebenslustiges Mädchen. Da sie aber mittlerweile keine Lust mehr auf Ärzte, Untersuchungen und Tests hat und sie sowieso schon viel mehr kann, als das MRT-Bild vermuten ließe, ist es sehr schwierig, offiziell festzustellen, wie weit ihre kognitiven Fähigkeiten eingeschränkt sind. Ohne diese offizielle Feststellung trauen die meisten Lehrer ihr aber zu wenig zu. Die entsprechende Odyssee der Familie ist unglaublich; sie ziehen von einem Ort zum nächsten, bis sie endlich eine Schule finden, in der Schuyler tatsächlich adäquat gefördert wird. Zu dem Zeitpunkt ist Schuyler 5 Jahre alt. Das Buch handelt auch primär von den ersten fünf Jahren, mit ein paar Rückblicken in die Zeit vor ihrer Geburt. Robert Rummel-Hudson schreibt sehr humorvoll und mit immer wieder durchklingender großer Liebe zu Schuyler, aber auch schonungslos offen über seine Selbstzweifel, darüber, da seine Ehe beinahe daran zerbrochen wäre, und über seine Versuche und Unternehmungen, Schuyler zu helfen, auch gegen den ausdrücklichen Rat diverser eigentlich hilfsbereiter, aber trotzdem nicht unbedingt in diesem Spezialgebiet bewanderten Pädagogen und Logopäden. Auch über die wildfremden Leute, die ihn und seine Familie aus seinem Blog kennen und der Familie zweimal in beispiellosen Aktionen Geld spenden, einmal, um einen Termin beim führenden Experten für Schuylers Krankheit wahrzunehmen, und einmal, um Schuyler eine Quasselbox zu kaufen, wie die Kommunikationshilfe liebevoll genannt wird. Ein absolut beeindruckendes Buch über eine Familie, die sich trotz aller Schwierigkeiten nicht unterkriegen lässt, und darüber hinaus auch noch sehr schön geschrieben. Ich kann es nur empfehlen :-)

0 von 2 Kunden fanden die folgende Rezension hilfreich. Within You, Without You Von BeatleBangs1964 "We were talking, about all the space between us." -- George Harrison, 1967 "The shortest distance between two or more minds is that of one's real voice." -- BeatleBangs1964 Robert Rummel-Hudson chronicles his life alongside that of his daughter, Schuyler. Schuyler, who was born on December 21, 1999 was the high note to a new and happier point in Rummel-Hudson's life. At that time, Rummel-Hudson had recently remarried after a marriage he described as being devoid of passion to a "perfectly nice" woman who was not his soulmate. From all outward appearances, his marriage to Julie appeared to be on rock solid footing. Readers learn a lot about Rummel-Hudson. One of 3 siblings, he unflinchingly describes his mercurial relationships with his siblings and their late father. He takes a forgiving tone when he said that his immediate family "used the tools" they had at the time, but the end results were the fault of no one. I like that. Rummel-Hudson, unlike Julie wanted to know his baby's gender. While Julie was convinced they'd have a son whom she'd name Jasper, Rummel-Hudson never divulged that he had the medical staff tell him Schuyler's gender from the sonogram. As a concession to Julie, Rummel-Hudson buys a large toy bear whom they call Jasper in anticipation of their first child. The name Schuyler was chosen for a daughter as a nod to her Dutch heritage. As she grew into her first year and not into speech, her name became even more meaningful. She was the unexpected trip to Holland when the travelers were planning to go to Italy. She was the unexpected source of treasures when another type of treasures were expected. I thought it was so adorable that Schuyler had an aversion for stuffed toys during her infancy. She had an adverse reaction to Jasper the Bear and refused to have anything to do with it. I also thought it was quite adorable when Schuyler "coldly" tossed a doll back into a Christmas gift box her first Christmas. In time, she appeases her father by playing with Jasper. Even then, she carries the toy in an inverted position, never seemingly sure quite how he wants her to play with it. Since she didn't like stuffed toys, it would have been a better idea not to get them for her and to put the ones she had away instead of leaving a few out. I didn't like the way the stuffed toys were seemingly pushed on her. She was very adamant in how she felt. Schuyler's absence of speech and speech development became alarming over the course of her first year. Tests failed to yield any diagnosis or treatment plan that seemed viable. By 2003, Schuyler got to do some traveling - a move from her native Michigan to New Haven Connecticut and a later move to central Texas. It was in 2003 that Schuyler was diagnosed with the congenital condition of polymicrogyria, which Rummel-Hudson calls her "monster." A monster is a fear of the unknown; often, an amorphous or grotesquely shaped oddity that inspires fear. The "monster" in this case was a rare condition that robbed Schuyler of her ability to speak. One cannot help but feel cheered by Rummel-Hudson's love for and final acceptance of his child. Julie mourns Schuyler not having siblings as she fears any subsequent child will have polymicrogyria. In addition to the delayed speech, Schuyler shows some developmental lags as well. She was nearly 5 before she mastered toileting and other self-care skills. Schuyler appears to accept herself as she is and her peers in the various schools she attended appear to enjoy her as well. One setback Schuyler encountered was when her speech teacher refused to learn sign language so that Schuyler would have this method of communication. Another setback Schuyler encountered was when her school refused to buy a device called the "Big Box of Words." The device involved typing on its screen, which then activated the "voice" that the words trigger. Rummel-Hudson's faithful network of bloggers on his website band together and raise money for the Big Box. Schuyler and family find their niche in Plano, Texas which is in the Dallas area. Schuyler is described as thriving in the Plano school district and even has fun with her Big Box. Schuyler's humor develops as she jokes and plays with expressions and things she found funny. She fills the metaphysical space between herself and others with her newfound voice! She liked making monster noises with it and even unleashed anger at another child who mocked her on a playground. At last, Schuyler

found her own voice! Having one's own voice is a large part of one's identity. Being able to communicate by whatever means necessary one's true thoughts and feelings and reactions instead of merely echoing the party sentiment is very empowering. It also engenders respect and helps one to forge their own identity. "Within You, Without You," a 1967 masterpiece by George Harrison is the soundtrack that underscores this book. Schuyler's story is about acceptance and paternal love. "When you've seen beyond yourself, then you may find that peace of mind is waiting there." -- George Harrison, 1967

Kurzbeschreibung 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. From Publishers Weekly 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. Pressestimmen Advance praise for Schuyler's Monster: "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" "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. 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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

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