

## Author Robert Rummel-Hudson moves his family to Plano for his special-needs daughter

**S**CHUYLER IS A PRINCESS whose story is unlike most, and unlike most fairy tales, the monster in her story is one she cannot see or touch or even run away from. It is Bilateral perisylvian polymicrogyria (BPP), a rare neurological disorder that affects her speech. After five years of doctor visits and one alarming parent-teacher conference at a school in Austin, **Robert Rummel-Hudson** and his wife **Julie** moved to Plano to try to slay the beast.

Published by St. Martin's Press (New York), *Schuyler's Monster: A Father's Journey with His Wordless Daughter* covers Schuyler's first seven years battling BPP. "The book focuses on the things that Schuyler

taught me," said Robert, "like to believe in my parental instinct, to trust my gut. There were many times when she received a misdiagnosis that didn't feel right."

Schuyler's original diagnosis was an Autism Spectrum Disorder, but Robert and Julie questioned the experts at Yale Child Study Center, and sure enough, an MRI revealed the true story: Schuyler was one of 40 BPP cases in the world.

For the world to understand this 3-and-a-half-year-old, Schuyler would need an Alternative Augmentative Communication (AAC) Device. They were around \$7,500 and through an

of the ATT, and she invited them to Plano.

Julie was nervous, like any mom in her situation would be, and told Robert, "I feel like we're chasing something we're never going to catch."

But upon their visit, the husband-and-wife team learned that Schuyler could be placed in a classroom exclusively for users of AAC devices. Plano's AAC program at Gullidge Elementary School would give Schuyler a sense of community.

The 8-year-old told *Plano Profile*, "I—am—in—the—third—grade," and smiled with a grin as bright as her red hair.

"What's your favorite thing to do at school?" her dad asked.

"I—like..." she paused, "M—A—T—H."

"Seriously?" both of her parents laughed.

Schuyler continued, "My—favorite—colors—are—pink—and—purple."

"You're giving away all your secrets, aren't you?" Julie nudged her daughter.

Julie is a public relations specialist for Barnes and Noble (on 15th Street and Alma), and Robert is the Director of Communications for the School of Architecture at UT Arlington, his alma mater. Robert majored in music at UT, but switched to English with no notion of becoming a published author.

**N**O DEGREE can fully prepare a parent to care for a special-needs child. What continues to be a challenge for Robert, he said, is knowing when to step back and let Schuyler be Schuyler. "It's hard not to want to do everything for her. I want to build this safe space for her."

The author wrote *Schuyler's Monster* to spell out his love in a wordless world. "My editor jokingly asked me if Schuyler was going to write a rebuttal one day," he said and added, "I wanted to write something for her in the hopes that one day she'd understand, even though I was fumbling in the dark a lot, everything Julie and I have done is out of love for her, to make things better for her."

Robert admires Schuyler's compassion the most. When she started school last year, he and Julie received a phone call about one of her wheelchair-



Robert Rummel-Hudson and his daughter Schuyler.

Profile photo

online fundraising campaign, Schuyler got her "voice." Now all she needed was a school that would back Assistive Technology.

Schuyler was attending a school in Austin, but a parent-teacher conference revealed that an impatient teacher was turning off Schuyler's device. Once again, she was left voiceless.

Finally, a friend told Robert and Julie that the Plano Independent School District had an Assistive Technology Team (ATT) that supported speech devices in the classroom. They contacted Sherry Haeusler, head

bound classmates who was getting picked on. "The teacher said, 'The second thing Schuyler did was inform a teacher...but the first thing she did was knock this kid in the dirt.'"

Robert laughed and admitted he was proud. "I remember high school. I was a fat kid in band and got picked on. Having a disability is a whole different minefield. I think her compassion and independence is going to serve her in the future."

Julie added, "I admire her tenacity. She's doing soccer now for the Miracle League in Frisco and she just jumped in there and figured things out."

Schuyler's tenacity showed through when she was learning how to write her name. Robert and Julie were told that she would never be able to write. "Now, every time I have a book signing, she's there signing books with me," said Robert, "and every time she signs a book, it's like this little personal victory."

He added, "There was a list of things she would 'never' be able to do. Since she's come to Plano, she's been crossing that list off one item at a time."

Robert and Schuyler will be signing books at the Prestonwood Barnes and Noble at 1 p.m. on Saturday, November 8. Then, they're off to the American Speech and Hearing Association in Chicago as guests of Prentke Romich, the company that makes Schuyler's device. (Visit [prentrom.com](http://prentrom.com) to see Schuyler's picture.) For more information on *Schuyler's Monster*, visit [schuylersmonster.com](http://schuylersmonster.com). ■

— BRITNEY PORTER

## excerpt

From the prologue to *Schuyler's Monster: A Father's Journey with His Wordless Daughter*

The first time we met Schuyler's monster, it lay waiting to pounce, not from behind a rock or from the mouth of a cave, but peeking out from between the lab coats of two nervous and sad-faced doctors....



read more of this excerpt on [planoprofile.com](http://planoprofile.com)

# THANK YOU PLANO

## for your warm welcome.

### Helping you fight heart disease

*Our extraordinary cardiac care isn't just about focusing on the heart, but focusing on the person. To us, it's personal.*



*On the Leading Edge in Diagnostics and Treatment*

## HEART FIRST



**Phillip E. Burket**  
MD, FACC

**James S. Rellas**  
MD, PA, MS, FACC  
Medical Director

TEXAS CLINIC AT PRESTONWOOD  
6957 W. Plano Pkwy at Marsh Lane  
Suite 1000, Plano, Texas 75093

- Cardiac Consultations
- Blood Pressure Management
- Cholesterol Management
- Cardiac Ultrasound
- Nuclear Cardiology in Fully Accredited Labs
- Stress Testing
- Coronary Calcium Scoring
- Dual Source (128-Slice) Coronary CT Angiography
- Invasive Cardiac Catheterization
- Pacemakers
- Sleep Disorder Care

FOR AN APPOINTMENT, CALL  
**972.939.8294**  
[www.heartfirst.md](http://www.heartfirst.md)

## LIFE CAN BE BETTER!

SOLUTION ORIENTED THERAPY  
Individual • Family • Couples • Adolescents

- Relationship Healing
- Helping Adults & Children Cope With Divorce
- Co-parenting/Blended Families
- Anxiety, Depression, Grief
- Anger Management
- Stress Management
- Trauma Recovery

**(972) 824-6177** Day, Evening & Weekend Appointments

5172 Village Creek Drive, Suite 101, Plano, TX 75093

[www.maryaliceradtkeLPC.com](http://www.maryaliceradtkeLPC.com)



MARY ALICE RADTKE, M.Ed.  
Licensed Professional Counselor  
National Certified Counselor  
Licensed Marriage and Family Therapist