


Love Beyond Words

A father chronicles the daily battles he and his family face to help his speech-impaired daughter find her true voice **By Robert Rummel-Hudson**



When his daughter, Schuyler, was 18 months old, a simple question from a pediatrician (“Is she making any effort to speak?”) transformed Robert Rummel-Hudson from befuddled new dad into the last thing any father or mother ever expects or desires to become: a special-needs parent. Eventually Schuyler was diagnosed, at age 3, with polymicrogyria—a rare brain malformation that can result in symptoms ranging from problems swallowing to grand mal seizures and varying levels of retardation. In Schuyler’s case, it has affected her ability to articulate words. For several years, Rummel-Hudson has blogged about his journey with his daughter, who now attends school and communicates with the help of a computerized box she carries with her. “When the doctor gave us the diagnosis, it was as if the bushes parted and out stepped a monster,” he recalls. “The dreadful thing in Schuyler’s head had a name.” While fighting his own depression and the nagging sense that he was not the right person for the job, he became an advocate to help his child cope with her disability. Here are posts from Rummel-Hudson’s ongoing blog (www.schuylersmonsterblog.com). →

Eighty-four Keys

January 14, 2007 We had our monthly parents meeting last night at Schuyler's school. It's always an interesting and humbling experience for Julie (Schuyler's mom) and me to spend time with other special-needs parents. It serves as a reminder that most of them—well, all of them, actually—have tenacious and smart kids who, in their individual ways, are nevertheless either slightly or significantly worse off than our daughter. Schuyler is the luckiest of unlucky kids.

Before the meeting began, the two members of Schuyler's Assistive Technology team who have been working with her from the beginning pulled us aside. They told us they think Schuyler is ready to move up to the next level on her Alternative Augmented Communication (AAC) device—a portable touch screen with programmed word keys that allows her to express herself and respond to questions audibly. "She needs more words," they said.

Schuyler's speech device is currently set to display 45 keys at a time. This new setting will bring it up to 84 keys, which is the maximum on her device, known hereabouts as her Big Box of Words (BBoW). Schuyler will be using the same setting as adults who use this device.

Well, I can't begin to tell you how happy we are—happy and proud and, most of all, vindicated. When she attended her little Austin-area elementary school two years ago, the district insisted it was unlikely Schuyler would be capable of using this advanced device. Although they never said so, Julie and I always suspected the reason they kept lowballing her



Clockwise from top: An adorable cipher at age 3; in fairy costume with Dad; a secure second grader



had as much to do with budget constraints as anything else. Updating Schuyler's device would cost thousands of dollars.

Rather than admit that or deal with the funding issue head-on, they claimed Schuyler was incapable of using the BBoW at all. ("Not educationally necessary" was the phrase I remember most vividly.) Not even two years later, she's moving up to the most advanced setting. It's worth saying again (and if you're a parent out there with misgivings about what your kid's teachers are telling you, I hope you're listening): *They were wrong, and we were right.*

If we'd stopped fighting that fight, Schuyler would still be sitting in a cramped little special-ed class, trying to teach sign language to her teachers who didn't know it. She wouldn't be educated so much as taken care of, and when she reached the age of 17, she would leave them, not as a high school graduate but rather as Not Their Problem.

Instead, she's in first grade, doing the same work and taking the same tests and obsessing over the same Hello Kitty merchandise as all the other 7-year-olds.

Underestimating Schuyler will bite you on the rear every single time. It's becoming clear that she might just be the smartest one of us all.

Mermaids

January 20, 2007 We were at Target today, buying clothes for Schuyler. As we wandered the store, we ended up in the DVD section, where Schuyler spotted *The Little Mermaid*. We realized she had only seen the crappy TV-series version, never the movie itself, so her mom and I got it for her, because we're swell.

It's definitely been a few years since I'd seen *The Little Mermaid*, long enough that I'd forgotten the deal that Ariel makes with Ursula, the giant, squid-legged drag queen, to give up her voice in exchange for some legs.

Schuyler was already captivated by all the mermaids, but when Ariel's voice was taken away, something occurred to Schuyler—something she's never actually come out and addressed with us. For the first time in her life, Schuyler *told* us that she can't talk.

She pointed to the TV and then pointed into her open mouth while shaking her head. She then gestured to just herself, again shaking her head. “I don’t talk,” she said over and over again in her strange, no-consonant language that we can usually understand but which is pretty much Martian to the rest of the world.

Later, when Ariel got her voice back, Schuyler turned and looked at us with an unreadable expression. But after the movie, she clearly wanted to discuss the issue further, and continued to tell us with gestures that, like Ariel, she had no voice.

When her mom reminded her that she had her BBoW to speak for her, Schuyler very carefully searched for just the right words, typing out “no mouth” at first, but frowning and deleting her unsatisfactory choice. I don’t think she knew exactly what

up on us, and leave us pondering long after Schuyler has grabbed the evening’s carefully chosen dolls and climbed the ladder to her bed.

I can only imagine what she dreams about. Perhaps she speaks in her dreams, as she does in mine.

Coffee Talk

April 8, 2007 Sometimes we do things for Schuyler that help her along in the world. We make decisions and sacrifices that turn out to be the right ones and which propel her down smooth, bright roads.

Most of the time, however, she pushes herself down those roads.

The other day, we took Schuyler to a huge play area at a semi-fancy local mall so she could run around and play without being subjected to (or subjecting her parents to) fried “foods,” cheap Happy Meal toys, or demented clowns. It was one of those new trendy playgrounds made of squishy giant forms that the kids can climb around on and fall off of without incurring litigation.

Schuyler defies expectations; on a 1-to-10 scale, she’s living her life turned up to 11

At this particular play area, the theme was “giant breakfast.” A 20-foot plate held a steak the size of a mattress along with two wagon wheel-size eggs. A slice of grapefruit was topped with a cherry as large as a basketball.

It is a very cool playground.

Schuyler was having her usual great time on the Big Breakfast; I think it’s probably her favorite place to play, with the possible exception of the oft-requested Clown House o’ Happy Meals. It wasn’t long before she’d made some friends. In this

case, it was two sisters who wanted to run around the giant plate, alternately chasing and being chased by Schuyler, and their brother, who kept up as best he could despite a cast on one leg. After exhausting themselves, the four of them climbed into the giant, Jacuzzi-size coffee cup and began the whole “So who are you and what’s your scene?” discussion. Before it got very far, Schuyler ran over to us and grabbed her BBoW.

What happened next stopped us in our tracks. And by “us” I don’t mean just Julie and me.

As Schuyler began demonstrating her device and asking questions of all the kids present, the adults watched in wonder. Four, then six, then eight kids crowded around the giant cup, fascinated by this hard-playing, hard-laughing little girl with the robot voice. I think the grown-ups worried about the Revolution of the Small beginning at that moment.

At the center of it all was Schuyler. She asked everyone their names and how old they were, and she answered

their questions as best she could. She led a cyborgian rendition of “Old MacDonald Had a Farm.” And when one little girl repeatedly tried to reach over and take the BBoW, Schuyler told her “No” and sternly pointed at the ground outside the cup until the little girl glumly climbed out and skulked away.

Banished by the Cyborg Princess. It’s a harsh world in Schuyler’s Coffee Cup.

For a full 20 minutes, Schuyler held court. I could see at a glance that while the kids were all fascinated →



she wanted to say, only that she saw something that resonated with her own life, and wanted us to understand.

I feel a heavy sadness about the evening, the same way I do every time Schuyler faces a harsh reality. Still, I can’t help but think that something really important and positive happened tonight, even if it was accidental. That’s usually how Schuyler’s big moments happen. They sneak

by and even envious of Schuyler and the BBoW, their moms were a little freaked out.

That's how it usually happens. If someone gets spooked by Schuyler or her monster it's almost always another adult, as if their kid might catch whatever she has. Kids her age tend to absorb what's different, make quick adjustments in order to facilitate play, and then go on.

Can't talk? Well then, let's run around and howl instead.

Secrets

May 14, 2007 Sometimes, I get a sense that people are hesitant to tell us they're having a baby. I can understand why.

Our friends know that we wanted a second child, but we've never been comfortable risking it, even though we've been told the odds of recurrence in a second child are relatively low—anywhere from 3 to 10 percent. (We never trust those projections, though. Not entirely.) We've made peace with that, I think, and yet there is a bittersweet tug when talk turns to babies. Julie and I always thought that Schuyler would have made an incredible big sister.

Polymicrogyria is not a disease—it's an umbrella term for a number of neurological disorders, all caused by the deformity of the folds (gyria) in the brain's surface.

We've read too many sad stories of kids with symptoms much worse than Schuyler's. Gambling with that possibility was more than we were willing to do. And of course there's the ever-present likelihood (85 to 90 percent) that Schuyler's current success and sweet, happy life will be rudely interrupted by epileptic seizures, maybe bad enough to hurt her.



Maybe worse than that, even.

Schuyler doesn't know how spooky the future is, but even if she did, I can't imagine she'd give a damn. She cheerfully defies expectations, takes up the fight, and is not complacent, either in school or in her continuous quest for perfect play. On a scale of one to 10, she's living her life turned up to 11, regardless of my own parental shortcomings.

I know that when I was an expectant father, seeing children with disabilities bothered me, although I would have been ashamed to admit it. I wouldn't have wanted to face that future, and I especially wouldn't have wanted to give much thought to whether or not I was up to the job as a father. Seeing how things could go down is hard. Wondering how they're going to be even without that possibility is hard enough.

No, I wasn't ready for this, but then, I wasn't ready for any of it. I wasn't ready for Schuyler to turn yellow a few days after she was born (jaundice—a common newborn condition, I know now), requiring the funky Jedi-light blanket on Christmas Day to lower her frighteningly high bilirubin levels.

I wasn't ready for her to run head-first into a shelf at Borders one day and give herself a mild concussion when she was just learning to walk (in that "walk means lurch at high speeds" phase).



Using her speech device or a favorite tee, Schuyler gets her message across

I certainly wasn't ready to sit up with her in the hospital after her emergency surgery to relieve a

painful abscess brought on by a nasty staph infection.

It hasn't just been her monster that snuck up on me.

But here's the thing. I also wasn't prepared for the first time Schuyler noticed my sadness at something and took my hand, kissing the back of it and patting it gently. I wasn't ready to hear "My name is Schuyler" come out of that first primitive box of words two years ago. Nor was I prepared to learn that she knew how to spell her own name (at a time when her teachers believed her to be unreachable) simply because she just started spelling it one day while we were sitting at Barnes & Noble eating a cookie. And I don't believe that Julie was ready to hear Schuyler say "mama" successfully for the first time a few weeks ago. (If she's not thinking about it, it comes out "mama." If she's trying, she trips herself up a little, coming up with "mwa-mwa." And "daddy" is just out of reach for now.) I wasn't ready for any of this.

Even if you get a child who talks and who does everything in the world exactly right and meets your every expectation (selfish and otherwise), that kid is going to have unfathomable secrets.

Schuyler carries more secrets than most, but every now and then she

will share one, and those moments, more than anything else, make my life worth living.

Rough Transition

June 5, 2007 Schuyler had a bad day at her summer program. She has an incident like this about once a year, which is probably not too bad for a soon-to-be 8-year-old.

Today she got frustrated and kicked a kid in her class, and then one of the adults as well. I'm still not sure we've gotten the whole story, but she admitted to the kicking on her BBoW. She said the boy hurt her first, but she didn't have an explanation for kicking the staffer. She shrugged miserably when we asked her why she did it, because I don't think she understands having a temper, or how to respond to her own frustration.

It's a particular difficulty with nonverbal kids, especially when they are interacting with new people who don't understand how to communicate with them. That doesn't excuse Schuyler's behavior, but this sort of thing doesn't just occur in a vacuum. The BBoW requires patience from everyone, since it takes her some time to respond to questions or express what she's feeling.

Well, it's only the second day.

She promised to apologize on her device to the people she kicked and to be the very best little girl she can be tomorrow, and I believe she'll do just that. After our long talk and mutual agreement on her punishment this evening—no TV—and what would happen tomorrow if things don't improve, she looked at me sadly and started punching buttons on her device.

"I love you," she said.

"I love you, too, Schuyler," I said. "I love you so, so much."

She smiled for the first time all evening and climbed out of her chair. She came over and put her arms around my neck and hugged me as hard as she's ever hugged me, and for a long time.

Future Girl

June 12, 2007 For the past few days, I've been listening to the audiobook of Anne Lamott's *Plan B: Further Thoughts on Faith*. I'm a big fan of Lamott, even if we've arrived at different places spiritually, and I was a fan even before we had Schuyler or →

met the monster. A passage from the chapter called “Diamondheart” jumped out at me. Lamott writes about her son, Sam:

“I can see myself so clearly in him, many of my worst traits, some of my goodness. I can also still see many of Sam’s ages in him: New parents always grieve as their babies get bigger, because they cannot imagine the child will ever be so heartbreakingly cute and needy again. But Sam is a swirl of every age he’s ever been, and all the new ones, like cotton candy, like the Milky Way.”

When I heard that, I realized that the same is true of Schuyler, and no doubt of every other kid as well. When I look at her, I can see the newborn she was, back when she was fat as a slug and covered with strange black hair, like a baby Wookiee. I can see her as a stumbling toddler, her body already starting to lengthen, her transition from baby to girl beginning, yet with those fat cheeks remaining. When I look at Schuyler, who has become a rambunctious, leggy tornado of a girl, I can see the baby I wore against my chest, shortly after moving to Connecticut,

shielding her impossibly tiny body from the bitter cold blowing in from the Long Island Sound. She remains all those Schuylers to me.

Some moments I can even see into the future. I can see, like ghost images in a photo in which the subject moves too fast for the shutter speed, the shadow of a pretty teenager who speaks like a robot but still makes that face at boys and causes them, and me, heartbreak and despair. When we’re out these days, I sometimes see teenage girls who are embarrassed by their fathers, and others who still cling to them unashamedly, and I suspect Schuyler will be a little of both. I can see her a decade from now, still dressing against the norms of the elite girls of North Dallas, where we live now, yet maintaining her outsider “cred”—the oddball stunner who carries her cyborg voice in a stylish bag and doesn’t wait to be told how to be cool. Sometimes I can even see Schuyler the young woman, the one who’ll go to college or go out into the world and make a place for herself on her own terms. In my most selfish dreams, Schuyler the young woman will be a writer, and she’ll

pick up the thread of chronicling her amazing and unpredictable life after I am no longer around to contribute.

Of course, I can’t divine what Schuyler’s life will really be like. I can’t even begin. But sometimes she’ll look into me with those eyes, the eyes of a child wise beyond her years. When she does, I can see the person she’ll grow up to be, the wild and broken and astonishing and perfect woman she was born to become. Schuyler looks more and more like her mother as she grows older, but I see so much of myself in those eyes, and in that crooked smile she flashes right before she does something that causes everyone in the room to hurriedly say, “No! Nononononono! Give me that!...”

When people ask what I do, I tell them I’m a writer. But the truth is, I am Schuyler’s father, her launchpad, and when I reach the end of my days, I hope she’ll be standing there beside me to send me on my way. ■

Robert Rummel-Hudson is the author of Schuyler’s Monster: A Father’s Journey With His Wordless Daughter, out this month.