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Jake's Sweet Blue Ride

by Eileen M. Cunniffe

Jake was not in the mood for his morning ritual. And who could blame him for balking at having his bladder emptied through a catheter, being strapped into leg braces then helped into his clothes, being served a breakfast that most likely would not stay down, having to swallow the pink and blue medicines and then puff three times on an inhaler? Along the way his short blond hair was styled into “spikes” and many smears were wiped from his eyeglasses. And all before 7:30, so Jake could pull himself into the bright blue wheelchair with a Power Ranger backpack draped over the handles, then roll through the kitchen door and down a ramp to the compact yellow school bus with a hydraulic lift.

Most days Jake goes along with it all. At seven, he’s old enough to understand—at least in basic terms—why each part of it matters. He knows right down to the toes he can’t feel that everything his parents and two sisters do for him (or to him), they do with love. He pays them back a thousand times over with smiles and hugs, giggles and sticky juice-bag kisses, impishness and gross-out humor, the latter often at his own expense.

But on this particular Monday, Jake was not complying. Facing the first full week of first grade, his protests ranged from under-his-breath complaints of “not fair” to a teary refusal to even consider breakfast. Twelve-year-old McKenzie couldn’t persuade him with big-sister logic. Nine-year-old Samantha couldn’t cajole him with reminders of recess. So Jake’s mom, Amy, five weeks into her husband Kirby’s latest out-of-town assignment with the U.S. Army, pulled an ace from her sleeve. She promised Jake a big surprise after school if he would just get on the bus and try to have a good day. She deflected his attempts to guess what the surprise might be as she wiped away his tears, realigned his glasses, kissed his splotchy pink cheeks and steered him toward the bus.

Amy, my sister, told me about the rough start to this day over lunch. While she’d been coaxing Jake into the world, I’d been making the three-hour drive to their house. I knew what was up, as did virtually everyone

in the small military housing development where they live. Only Sam hadn't been told, because everyone knew she could not withhold a secret from her Jakie.

Jake has spina bifida. On the day he was born, he was whisked from the delivery room into a surgical suite for a five-hour-long series of surgeries to close a hole in his spinal cord and to place a shunt behind his right ear to drain excess spinal fluid away from his brain and into his stomach. He's had more than a dozen other surgical procedures since—to align his feet and knees, to adjust muscles around his hips, to replace the original shunt (twice so far) and to correct a problem with one of his eyes. He will require additional operations over time, for orthopedic, gastrointestinal and neurological problems and, with luck, for scientific breakthroughs that might alleviate his physical challenges.

Jake's legs don't work below the hips, and he has no sensation in them. As he once explained to me in a sarcastic voice, rolling his eyes for effect, "Apparently, my legs are broken." He often has trouble swallowing food, or keeping it down—"I have a gag reflex," he explains. His bladder and bowel functions are badly compromised—"my private stuff," he says now that he's old enough to feel self-conscious. Jake has received physical therapy since he was an infant, which develops his upper body strength and briefly allowed him to walk, at least a little, with an elaborate system of braces and other supports. Jake has learned to maneuver a series of progressively larger wheelchairs, the first when he was just two years old. He's always referred to the chairs as his "wheels."

People in Jake's life take their cues from Amy and Kirby, who from the beginning chose to celebrate Jake's abilities and nurture his spunkiness. There was already a lot of laughter in their household before Jake was born, and things have gotten even funnier since he started talking. Because of the way he handles himself, people accept the wheels as part of the overall Jake "package"—along with his spiked hair, his wacky sense of humor and his uncanny ability to memorize movie dialogue. Jake attends regular schools, played on a t-ball team one summer and gets into at least as much mischief as any other boy. He's had some of the best Halloween costumes on record, including a race-car driver and a motorcycle dude, both of which incorporated his souped-up wheels.

Among Jake's acquaintances are a few dozen members of the U.S. Marine Corps who are stationed at the same base as Kirby. Jake likes to go to the gym with his dad. Sometimes he lifts hand weights and does push-ups. Mostly he just holds court. When the Marines stop and chat with Jake at the gym, he

challenges them to strong-man competitions. He is confident he could take them on and win. The Marines get this about Jake, so they urge him on while he exercises. They also return his high fives and laugh at his amazingly bad knock-knock jokes. Last summer, one of them taught him to swim the length of the pool; it would be hard to say who benefited most from those lessons.

When the Marines learned there was a special kind of bicycle available for people like Jake, a bicycle pedaled by hand and designed for anything from plain old fun to competitive racing, they made it their mission to get him one. They sold hot dogs at local sports events, tapped into other community service funds they had raised and made personal contributions to come up with nearly \$1,600 to buy Jake a custom bike. By the time Amy and Kirby heard what they were up to, the bike had been ordered—in Jake’s favorite color, electric blue. Amy, who loves how Jake inspires other people, quickly spread the word to relatives and friends around the country about the bike-to-be.

I was waiting at the curb when Jake’s bus pulled up after school that Monday afternoon. His jaw dropped, his eyes popped, he slapped his forehead. He could hardly wait to be lowered from the bus to give me a monster hug. In his mind, I was the surprise he had been wondering about all day, and in Jake’s world, an unscheduled visit from his godmother made for a pretty fine afternoon. He was full of ideas for what we could do—play games, watch movies, make spaghetti for dinner (and breakfast, too). He was glad I was staying overnight, but immediately began lobbying for a longer visit, one with “a whole lotta nights.” I was happy to be a decoy for the real surprise, an extra twist in the plot.

We hurried the kids through homework and snacks, as well as Jake’s after-school catheterization and meds. Amy offered a vague explanation of something we had to do on base, which Jake and Sam considered to be a supreme waste of perfectly good aunt time. Despite their protests, we piled into the family’s oversized van, equipped with a wheelchair lift. While McKenzie and Sam scrambled around Jake to strap his chair into place, we had another good laugh about what a surprise it had been to find me there after school, when it wasn’t even anybody’s birthday.

On base, we pulled up beside a large hangar as uniformed Marines and soldiers, moms, off-duty dads in civvies and assorted kids scurried through the door ahead of us. Inside, about a hundred people were gathered and the air buzzed with anticipation. Huddled in the middle of the large, sterile space were about 30 Marines—men and women, mostly young, all in

uniform. Some were fresh off guard duty and still clutched their rifles. While kids chased around the hangar and women lined up cookies and brownies on a table, the Marines stood their ground, a tight little cluster, their faces all business despite the otherwise carnival-like atmosphere

Two senior Marines stood away from the group, and as we entered the hangar, one of them called Jake over to his side. “Mr. Fred,” as Jake calls him, asked everyone for their attention, then asked Jake what he thought was going on. Jake shrugged his shoulders, rolled his eyes and glanced slyly toward the table of treats, still unaware that he would be the star of this show. Waving toward the Marines, Mr. Fred explained they had decided to hold a contest to determine who was the coolest kid at the base. “And you know what, Jake? Every one of the Marines voted for you,” Mr. Fred announced. Wide-eyed, a little embarrassed by the attention, but not at all surprised at having won a contest he didn’t even know he was in, Jake politely thanked Mr. Fred.

Then Mr. Ray stepped forward. “Jake, we thought you should have something special for being the coolest kid, so the Marines all got together and now they want to show you what they got for you,” he boomed. He directed Jake’s attention to the group in the center of the hangar. As Jake rolled toward them, his mom and sisters close behind, the Marines parted, revealing an electric-blue, low-slung bicycle in the midst of their tight little circle. “Sweet!” Jake cried. The crowd erupted with cheers and applause.

Jake didn’t hesitate for an instant, except to offer a hasty, “Wow, thanks, guys!” He immediately reached for the seat belt on his wheelchair, whipping it off so he could try his first-ever bicycle. Camouflage-clad arms appeared from everywhere, lifting him out of his chair, lowering him into the seat of the bicycle, strapping his legs into place, clipping a belt around his waist and placing a bright blue helmet on his head. Then, for the second time in as many minutes, the circle of Marines was broken. Some of them literally had to jump out of the way as Jake—not bothering to wait for instructions—wrapped his hands around the pedals and exploded into the crowd.

Cheers rang through the hangar as Jake powered the shiny blue bicycle into a wide-open space. A pack of children raced behind him, shrieking with delight, in part for the pleasure of hearing their voices echo in the vast metal cave. Grown-ups (and big sister McKenzie) dabbed at tears and clapped as Jake propelled himself toward the back of the hangar, then gasped as he sped toward a wall, not knowing how to stop his new machine. Rescued by nearby moms who slowed the

bike from behind, Jake and his fan club paused just long enough for a quick lesson on the hand brake, then set off again, tracing a wide and noisy circle around the perimeter of the crowd. The Marines—some of whom did not look too many years removed from their own first bicycles—stayed in the center of the room, turning as one to follow Jake’s progress around the hangar.

The bike was a wonder to look at, a masterpiece of engineering. Jake sat about six inches above the ground, a low, curved frame connecting the front wheel with two rear wheels, which angled out slightly at the bottom for stability. (The frame can be extended as Jake grows and will hold up to 250 pounds.) The pedals were on the same plane—unlike pedals on a regular bike, where one is up while the other is down—so it looked like he was rowing. At their highest, the pedals were even with Jake’s shoulders; at their lowest, they were a few inches above his outstretched legs, which were secured in small slings at the ankles, held safely away from the bike’s workings. The hand brake and gear shifts were under the seat. The gear wheel sat just below Jake’s chin, behind a plastic cover.

After a few laps everyone moved outside, where Jake raced up and down the empty airstrip, surrounded by a throng of supporters. He stopped to pose for photos with the Marines, with his sisters and mom, and with some neighbors. When he panicked slightly coming down an incline, firm arms once again slowed him from behind.

Finally, Jake stopped to catch his breath, sip on a cold drink and chat with his friend Brianna. She suggested they should eat dinner really fast, then meet at the tennis court with their bikes. Jake happily agreed, and it seemed to be just dawning on him that now he *could* ride his bike with the other kids, instead of trailing behind, working to keep up as they moved from one place to another. Brianna asked Jake what he was going to name his bicycle. It clearly hadn’t occurred to him that his bike needed a name, but he was happy to humor her. A brainstorming session ensued, helped along by McKenzie and Sam, who had been hovering near their brother throughout the festivities. Within minutes the ad hoc naming committee settled on “Jake’s Sweet Blue Ride.”

The crowd began to disperse. As Jake scrambled back into his wheelchair, a neighbor loaded Jake’s bike into his pick-up truck to deliver it to the house. As we left base, Mr. Fred pulled up beside the van on his twelve-speed bike. Jake challenged him to a future race, to which Mr. Fred happily agreed. Jake shimmied his shoulders and did a little dance in his wheelchair. “I

can beat him,” he crowed, as the van headed home.

While we ate dinner, Kirby’s friends e-mailed him photos and video footage of Jake receiving and riding the bike, so he was already fully briefed when Jake called. We listened in as Jake excitedly told his dad, “The first time I started to ride my bike it felt like I was flying. It was like aaaaaaaaahhh! All the kids were chasing after me and it felt amazing. I started to ride around the hangar,” he reported, “and it was feeling good. I felt strong and strong. I was going super fast.”

Brianna met us after dinner, as promised. Sam brought her bike, too, while McKenzie flew around on in-line skates. They looped around and around the tennis court. At one point Jake crashed hard into the chain-link fence, but he laughed it off, observing, “That was not kinda good.” When he caught McKenzie holding onto the back of his bike he yelled, “Hey, there are no free rides here!” Then he scraped along the side of the fence and coasted straight into a corner. He hadn’t yet grasped that unlike his wheelchair, the bike didn’t go in reverse, so more than once he needed help getting unstuck.

After about twenty minutes on the tennis court, Jake took his act on the road. In their small development, the houses form two concentric circles around a private road and kids are constantly on the move during daylight hours. News of Jake’s maiden voyage preceded him and neighbors spilled out of front doors to cheer and get a closer look at the nifty blue bike. When a classmate who hadn’t been at the afternoon gathering ran over, Jake matter-of-factly explained he had won the bike for being the coolest kid. He lingered long enough say, “ I wish you could have won, too.” Then he sped off, shouting over his shoulder and taunting his mom and aunt to try and keep up with him.

Two laps later, a shirtless teenager ran into the street as Jake passed and yelled out, “Nice ride, Jake.” “Oh yeah, baby,” Jake replied, “This is my ‘sweet blue ride.’ Know what, Logan? I just ran into a stop sign. Ha-ha-ha!” (He had, too—although in slow motion.)

It went on like this for many more laps, with kids chasing Jake around the circle on foot or with their own wheels, and neighbors cheering him on from their porches. It was nearly dark when we finally persuaded Jake it was time to put the bike away. He reluctantly let us push him up the hill and into the garage.

We sat around the kitchen table, reliving the excitement through Jake’s eyes as he dripped his way through a blue popsicle and fielded incoming calls from grandparents, aunts, uncles and cousins. “It felt nice

when I was going around the hangar and everyone was clapping for me.” “I was going so fast and there was like wind coming in my hair and it was like *whoooooosh!*” “I got to talk to Dad and he already saw the pictures of me and my bike, but I got to tell him it was blue and I was going really fast.” Sam summed up the day for all of us: “At first I thought they were clapping for Jake because he is in a wheelchair. Then I knew they were clapping because Jake’s a great guy and he could win the cool contest any day.”

It was hard to stop talking that night, hard to stop remembering the fun we’d had, even after baths were taken, teeth were brushed and lights were out. In bed at last, Jake rolled onto his side and propped his damp head up on one arm. “You guys,” he said sleepily, “this was the best day ever.” We smiled at him in the dark, knowing that many of Jake’s days end with the same words, even when there isn’t a big surprise and even when things don’t look so hot over breakfast. Those of us who are lucky enough to hang out with this kid have learned that “strong and strong” is how you make it from one end of the day to the other, and that being cool goes a long way, too.

Eileen Cunniffe has been writing nonfiction for 30 years—but the first 25 of those were without bylines, as a medical writer, corporate communications manager and executive speechwriter. In 2005 she escaped the corporate world and began to write her own stories. Her essays have been published in *Wild River Review*, *400 Words*, *Philadelphia Stories*, *ShortMemoir.com* and the anthologies “A Woman’s World Again” and “Prompted.” Two of her travel essays have been selected as Solas Awards winners by *Travelers’ Tales*. She holds undergraduate degrees in English and Honors from Villanova University and a master’s in science from the University of Pennsylvania. She works at the Arts & Business Council of Greater Philadelphia.

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