AVI’s SMILE

by Sandra Weiner

Being funny runs in our family. My husband, Marc Weiner, is a professional comedian and a puppeteer. I'm an artist and a comedy writer. But even apart from our occupations, we both tend to look on the bright side. Maybe that's why, despite the fact that I'd miscarried once before, we looked forward to a healthy baby when I became pregnant again in 1985.

In fact, on the day of the delivery, Marc and I were joking through my contractions—once I'd had my epidural. I pushed out the baby with surprising ease for a firstborn.

Almost from the moment of birth, the atmosphere in the delivery room changed. It was suddenly anything but jovial. A nurse was pushing my head back onto the table to keep me from seeing the baby. The room filled with nurses and doctors. The baby was whisked upstairs to the neonatal intensive care unit, accompanied by my husband. All I knew was that I'd given birth to a boy; Marc and I had agreed that we would name a boy “Avi.” I was left alone, shivering, in the recovery room.

Eventually a doctor came in and told me that Avi had been born without an anus and that his thumbs dangled from each of his hands by mere skin. There was, in addition, the possibility of Avi’s having stomach, kidney, heart, and lung abnormalities. My first thought was, “I have a shell of a baby.” I was wrong, but I didn’t know that yet.

A Rough First Year

What made it so hard to accept Avi’s frailty as a newborn was that, at a birth weight of seven pounds, three ounces, he looked so much healthier than the premature babies in the nursery. And his face was that of an angel—an angel with a feeding tube in his nose, a colostomy bag for his bowel movements, several intravenous lines, and a kidney catheter.

After Avi had spent three weeks in the hospital, the doctors let us bring him home, but he was back a month later because of dehydration. The night he reentered the hospital, he had a major septic; a severe kidney infection sent him into the intensive care unit. His doctor called us into a closet—the only private place on Avi’s floor—and told us, “This is serious. Your son might die.”

Amazingly, Avi pulled through, but that first year of his life was filled with surgery: 13 operations in all, mostly to repair birth defects in his internal organs.

In our earliest pictures as a family, you can see in our faces how much Marc and I loved Avi, but it’s also very clear that we were exhausted. When he was around three months old, however, and we knew that Avi would survive, our mood—and our photos—changed completely. Overwhelmed with relief, we indulged our taste for silliness and took a series of photos of Avi in the outfits that Marc’s puppets wore. He was a cowboy, a sombrero-clad Mexican with maracas, a Blues Brother complete with saxophone and dark glasses.

The foolishness suited his temperament. For all his medical problems, Avi turned out to be a remarkably happy child. I now suspect that it might be because, when he wasn’t having surgery or recovering from an operation, he was simply happy not to be in pain. To our delight, he laughed and smiled at a normal age. Although his thumbs dangled uselessly from his hands, he quickly and cheerfully learned to manipulate objects quite well with his other fingers.

Between his various operations, we often took Avi on the road for Marc’s comedy appearances, driving for hours in a car packed to the roof with Avi’s various medical paraphernalia and medications. His needs were immense. Because he couldn’t keep food down, he had to be fed throughout the day by tube with a pump attachment that dripped formula into his stomach. Luckily we discovered that the apparatus fit very nicely onto the hook in the car door where most people hang their dry-cleaning. Along with diapers, I brought colostomy bags. When Avi had to be changed in ladies’ rooms, I did it in a closed stall because I was embarrassed about how other women might react.

During Marc’s shows, I would take a chair in the back of the room and Avi would sit on my lap, a strategy that worked until Avi got older and laughed and shouted more and more loudly. Although Marc and I were overjoyed at seeing him so happy, he distracted the audience. I felt terrible, but I had no choice but to take him out of the room until he calmed down.

A Name for Avi’s Disease

When Avi was about a year old, I became pregnant again. Because of Avi, and because I’d had a miscarriage before giving birth to him, it was important to me to know that I could have a healthy baby. It was a real blow when, several months into the pregnancy, we found out that Avi’s birth defects were not a fluke as we had originally been told.

Tests showed that he had Fanconi’s anemia (FA), a rare genetic disease in which the bone marrow produces severely reduced amounts of red and white blood cells. Without a bone marrow transplant, Avi had little chance of surviving to adulthood. No one in our family had marrow that was compatible with his, so there were no suitable donors. Not yet, anyway.
An amniocentesis indicated that the new baby probably did not have the disease, but until the blood from the second baby’s umbilical cord was tested at birth, we wouldn’t know for certain.

Being in the hospital with Avi as often as we were and seeing as many other sick children as we did, we couldn’t take it for granted that I would give birth to a healthy baby. Marc and I cried tears of joy when I delivered a healthy daughter, Rebecca. After my experience with Avi’s birth, it was overwhelming simply to be able to hold her and nurse her for as long as I wanted. The only thing that would have made us happier is if her marrow had been compatible with Avi’s, for the bone-marrow transplant.

He was not thrilled by Rebecca’s arrival. She was a fussier baby than he had been. She hated the car—which meant the end of the road trips that he loved—and she cried a lot. His jealousy was probably compounded by the fact that, within 18 months, his baby sister was bigger than he was. But there was an upside to having a sister; Avi loved parading around in Rebecca’s dresses and latching suits. We used to joke that on top of everything else, he was a cross-dresser.

Before he was 18 months old, Avi was sitting up, crawling, cruising like a pro—and just about ready to start walking. Unfortunately, at that point he had to undergo the first of two very painful operations to reset his hips in their sockets. For six weeks after each operation, he wore a body cast from his brachial to his feet, with a bar between his thighs to keep his legs separated. It was cumbersome, but Avi was determined to be mobile, even if it meant pulling himself along the ground by his elbows, dragging the cast behind him in what I referred to as the “Gil Joe crawl.”

The surgery didn’t work; one year later, Avi’s hips popped back out of their sockets. It was almost two years before he would even attempt cruising again. Walking was especially frightening for him because he had become old enough to be afraid of falling; it was also painful, because the operations left his muscles very tight.

Yet true to form, Avi eventually learned to walk in his one-of-a-kind way, a stiff, wide-gaited, Chaplinesque swagger. He took his first steps when he was almost four, while we were visiting a friend who happened to have a whoopee cushion. After laughing hysterically every time someone sat on it, Avi unexpectedly hauled himself up, determinedly walked across the living room, and plopped down gleefully as the cushion burst a big fat raspberry. For his fourth-birthday party, we put out a dozen whoopee cushions on chairs around the room. He trekked back and forth from one cushion to the next, exploding into giggles each time he heard the splat.

A Unique Sense of Humor

Whoopie cushions were an important part of the distinctive schtick—a Yiddish show-business term that means a performer’s routine, sort of his trademark—that Avi was developing. His was from the slapstick school of pratfalls, funny faces, and silly noises à la Jerry Lewis (one of his father’s favorite comedians). Among Avi’s best gags was pretending to talk, silently mouthing words in an exaggerated way. Another was collapsing in giggles when we pretended that we were blowing him down.

Our friend Marvin, a comedy writer, had a routine that Avi thought was the funniest thing going. Marvin would fake a very loud sneeze into a tissue and sent the tissue flying up into the air. Avi loved it so much that we filmed it. Whenever he was in pain, that tape would always cheer him up right away.

Avi was obviously good-natured, but we never really knew much of what was going on inside his head. Although tests showed that he had normal intelligence, he would almost never respond to a direct question unless we persisted. By age three, he knew all of his colors, his numbers, and his alphabet, and yet he never let on to people if they asked. Avi always looked so deep in thought that it frustrated us—we longed to be privy to those thoughts. I was waiting for him to get older so that I could ask him what was on his mind.

An Angel’s Voice, and a Genius for Words

Perhaps in part because he talked so little, music and books became an important part of Avi’s life. Practically from the day he was born, we bought him every musical windup toy and tape on the market. Even when he was an infant, I’d read aloud to him from whatever novel I was involved in at the time. With no effort at all, he could memorize his favorite books (he was particularly fond of Maurice Sendak’s In the Night Kitchen) and the songs that he loved. He amazed us at times by endlessly reciting and singing words that he would never use in ordinary conversation. Sometimes, in the middle of the night, we would wake up to the sound of him singing softly to himself. Sometimes it took an hour or so for him to sing himself back to sleep.

When Avi was about two, we enrolled him in a special school for children with disabilities. He loved it, and the feeling was mutual. His love showed itself, in its usual mischievous way, in a book he made in class called All About Me. Among the “things I can do and things I like,” Avi listed running, singing, hugging, playing with Teenage Mutant Ninja Turtles, and “making fun of my teachers.”

For a boy who didn’t talk much, Avi had strong likes and dislikes. After spending his first year on a feeding tube, he developed an aversion to eating. It upset us because he was already so small for his age. Some days he consumed almost nothing—a couple of bites of a cracker and a bit of cheese. He was far more interested in poking his fingers into pieces of ziti and pretending that they were fingernails, “smoking” his fish sticks, or playing tidy-winks with his Cheerios.

One day when he was two and a half, Avi put away 72 Rice Krispies at one sitting. It was the greatest
amount of solid food that he’d ever eaten. By the time he was finished, Marc and I were so happy that we made a tape-recording of all of us singing “It’s Avi Ate Day.” Everything came so hard for Avi—sleeping, eating, talking, voiding—that every one of life’s simple achievements was special and significant.

Still, there was never a question in our minds as to whether or not to fight for Avi’s life. When our third child, Max, was born—Avi was four by then—we hoped that his bone marrow might be suitable for the operation. It wasn’t, but Marc and I refused to give up.

A Sudden Illness

A few weeks short of his fifth birthday, Avi suddenly and mysteriously became very sick. What we didn’t learn until later was that he was suffering from a brain tumor. We rushed him to a local hospital. Still barely the size of an 18-month-old, he was very weak and dehydrated from vomiting. The doctors asked us again and again, “Does he talk? Does he walk? Does he have a personality?” I wanted to bring in a videotape and show them just how much of a personality he had. I wanted them to know that Avi was a child worth saving.

Eight hours or so after he arrived in the hospital, Avi began to have trouble breathing. His eyes were frightened. Marc and I fell back on a family tradition; whenever Avi was about to undergo an unpleasant procedure, we asked him to smile. It distracted him from his pain and fear. Marc said, “Avi, smile.” And he did. It was the last time we saw his precious smile.

A few weeks after Avi died, I received a telephone call from a wonderful woman named Maggie who had been a monitor on his school bus. She recalled how he always spent those long rides singing and laughing. Until she met Avi, she said, she had always thought of herself as a lonely, ill-paid bus monitor. But Avi, she said, made her realize how much love she was capable of giving, and getting. She told me, “I love what I do, and I’m never going to apologize for it again.”

Avi wasn’t forgotten by his friends, either. About a year after he died, we heard that Brian, one of Avi’s close friends at school, was talking to one of the school’s administrators. “Do you want to see my pictures?” Brian asked. He then pulled out a photo of himself with his arm around Avi. “That’s my best friend, Avi,” he said. “I used to help him do puzzles. I sleep with his picture under my pillow every night.”

Avi’s Legacy

I know for a fact that living with Avi gave our family a genuine empathy for other people, with or without disabilities. Rebecca in particular seems to have learned compassion at an early age. Not that she’s selfless—she has the normal egocentricity of a four-year-old—but I don’t think it’s a coincidence that she is the one in her class who always comforts the other children when they’re crying.

I still sit up in bed many mornings, hoping to hear the sound of Avi running to our room and see him climbing into our bed, saying, “Hi, Mommy! Hi, Daddy!” Marc and I now know that there’s nothing harder in the world than losing a child. But we also realize what a great gift we were given for almost five years. Because Avi insisted on taking such pleasure in life despite all his medical problems, we now understand that, as parents and as human beings, we can take almost nothing for granted. What we can do, however, is appreciate the miracle of our children.

At his funeral, we asked family members to eulogize Avi. I remember my mother mentioning not only how much we were all enriched by having him in our lives but also how he “sang with a sweet voice right on pitch and could tinker with a tape machine as well as any disc jockey.”

Afterward, at the cemetery, we wound up Avi’s favorite music box and placed it on top of his small coffin as it was lowered into the ground. As we all took turns shoveling dirt into the grave, the music played sweetly on and on, until it was finally stilled.