

## 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 setback; 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 a 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.