

READERS TALK ABOUT: Twins

A Matter of Perspective

Seventeen weeks into my pregnancy, an ultrasound revealed that our first “child” would be *twins!* Our excitement and anticipation were short-lived, however. Eric and Aaron were born at 26 weeks gestation—three and a half months too soon.

Our lives as parents certainly got off to a rough start, as did the lives of our boys, who were immediately whisked off to the neonatal intensive care unit (NICU). When we finally got to visit, it was difficult to see our babies among all the tubes and wires. They looked like little albino monkeys, covered with fine blond hair.

The boys spent the next three months in the NICU, a stressful roller coaster ride that can be truly understood only by other parents of “preemies.” Both boys had many of the problems common to prematurity, including hypotension (abnormally low blood pressure), respiratory distress syndrome, intracranial hemorrhages (bleeding in or around the brain), retinopathy of prematurity (an eye disorder), patent ductus arteriosus (a condition in which oxygenated blood flows back into the lungs rather than circulating to the rest of the body), hyperbilirubinemia (jaundice) and anemia.

Eric’s most serious problem was bilateral periventricular leukomalacia (PVL), a condition in which tissue around the brain’s ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen. Aaron needed a tracheostomy because of acquired subglottic stenosis (a narrowing of the area beneath the vocal cords and the opening between them), an unfortunate result of his earlier need for a breathing tube. Because of damage to his lungs and airways, he also had bronchopulmonary dysplasia, a chronic condition that would always affect his breathing.

The twins’ first year was pretty much a blur. Aaron, who was oxygen-dependent, needed 24-hour-a-day nursing care; Eric was a colicky, fussy baby who rarely slept. We knew Eric had PVL and would probably have a disability but had no idea how mild or severe it might be. Not knowing was the hardest thing to deal with; once he was actually diagnosed with spastic quadriplegia cerebral palsy, we could finally begin to cope.

Although Aaron’s problems are more acute now, his long-term prognosis is good; Aaron’s problems can be “fixed.” We no longer notice his tracheostomy; even to Aaron, it’s just a part of who he is—eyes, ears, nose, bellybutton, trach. At



Aaron and Eric Bissell are identical twins whose very different disabilities stem from medical complications associated with their premature birth. Aaron (left) has bronchopulmonary dysplasia and a tracheostomy; he is now oxygen-dependent only while sleeping. Eric (right) has spastic quadriplegia cerebral palsy.

the same time, Aaron’s more average motor skills are a constant reminder of what Eric might have been. They would be so cute running around the house together.

Despite their differences, the boys share a close bond. It is common for twins to develop their own private “language,” but because of Aaron’s tracheostomy and Eric’s severe speech delays, our twins communicate through an unusual “quacking” noise. Sometimes it sounds like we have ducks in the living room.

In many ways, Eric and Aaron are typical toddlers—each wants what the other possesses. Unfortunately, Aaron has an unfair advantage. As for Eric, I often joke that he never does anything wrong because of my *excellent* parenting skills, but I wish he *could* get into trouble sometimes. I don’t see myself as a strict disciplinarian, but I have no doubt that I am more lenient than I would have been if the boys had no problems. A friend watches nervously as Aaron stands on a dining room chair and asks, “Why do you let him do that?”

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. When readers will be talking about:

- **Positive health care stories:** Tell us about the health care professionals who have made a *positive* difference for your child and family. (August issue; deadline June 1)
- **Talking with your child about sex** (September issue; deadline July 1)
- **Family holidays:** How do you survive large family get-togethers when your family includes a child with a disability? What do you and/or members of your extended family do to help your family and child feel included? (October issue; deadline September 1)
- **When your child grows up:** Where will he or she live, and with whom? Share your dreams, plans and concerns. (December issue; deadline October 1)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

Glancing at Eric lying on the floor like a turtle on its back, I answer, "Because he can."

Richard and I are often asked how we manage. Well, "problems" are all a matter of perspective. I discovered this back in the NICU when we were told that Eric had PVL and Aaron would need a tracheostomy. I was paralyzed with worry and fear but gained some insight on my own situation by observing two

other mothers. One woman was upset because one of her twins was temporarily under an oxygen hood; the other was despondent because one of *her* twins had died. All three of us were grieving from different perspectives. I realized that although things could be better, they could also be much worse.

—Cynthia Bissell
Grafton, Massachusetts

Who Needs Me More?

Just two weeks before our third baby was due, Duane and I learned we were expecting two! While my husband frantically located a second bassinet, car seat and swing, I rested and read books on raising twins.

Emily and Elizabeth arrived just 10 days later. Beth, the smaller twin, seemed a little floppy and didn't nurse well initially, but everything improved within a few days and we all went home together. Her older brother and sister immediately gave her the nickname "Kitten," because her cry resembled that of a sad baby cat. We settled in, and I convinced myself all was well.

Still, on the advice of our family doctor, we visited a developmental pediatrician when the girls were a month old. I wasn't worried until he called in a geneticist, who measured Beth's head circumference and the distance between her eyes and then looked at the palms of her hands. The doctors told us they believed she had a chromosomal disorder known as "cri du chat," French for "cry of the cat." They described the syndrome's main characteristics—a cat-like cry, widely-spaced eyes, low-set ears, microcephaly and mental retardation—and ordered a blood test to confirm their tentative diagnosis. But in my heart, I already knew it was true.

My dreams were suddenly shattered—no little girls dressed alike for the holidays or heading off for their first day of school together. I struggled with conflicting emotions. On the one hand, I had the beautiful, bouncing baby girl I had dreamed of, a child who smiled at me and loved to cuddle. On the other hand, I had a tiny baby who cried most of the time, squirmed so much she was hard to hold and never made eye contact. I felt more drawn to hold and play with Emily, but when I did, I felt guilty about leaving Beth out.

I began to obsess about treating the girls equally, no matter what. Whenever I played with Emily, I turned to play with Elizabeth. If I gave Beth a kiss, I immediately kissed Emily as well. I felt particularly self-conscious at family gatherings. I couldn't let anyone believe I was playing favorites with my children, but inside, I was terrified that I really did love one baby more than the other. Emily was any mother's dream, but my heart nearly burst with pride and love as I watched Beth struggle to master the skills her sister learned without effort. I constantly asked myself, Who needs me more? Beth's needs were so much more complex, but Emily's simpler needs were important, too.



"All mothers of twins need to learn to accept their children as individuals," writes Laura Bruns. "This was easy for me; my girls have always been so different." Two-year-old Elizabeth (left, wearing an eyepatch to correct her weak left eye) has cri du chat syndrome, a chromosomal disorder; her twin, Emily (right), does not have a disability.

As the girls grew older, however, I found it easier to relax and enjoy each child for her own unique talents and gifts. All mothers of twins need to learn to accept their children as individuals. This was easy for me; my girls have always been so different. But as I watch Emily help Beth try to stand or get up on her rocking horse, I believe she recognizes the special bond they share.

While shopping with a friend recently, I saw a mother with twin daughters about the same age as mine. Briefly, I flashed back to my original vision of the life I would have with my girls, and tears came to my eyes. But when I arrived home that evening, Emily and Beth greeted me with smiles and hugs, and I said a prayer of thanks for the unique blessing that is my twins.

—Laura Bruns
Coldwater, Ohio
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