PERSPECTIVES

Our Puzzle

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I took my daughter Miranda to her 3-year-old checkup, expecting a routine examination. We had recently moved to town so it was our first meeting with Dr. Barrish, a young woman whose name I had found in the phone book.

Later I would curse Dr. Barrish for changing my life forever. I would describe her as a scientific fiend crying, "Eureka! I got an interesting one!"

That day, though, I answered her questions ingenuously, not realizing she was gathering evidence. No, Miranda doesn't speak in sentences very often. She's quite different from her brother who has always been a chatterbox. We assume that's because we lived abroad from the time she was 1 until she turned 2. No, she doesn't resemble my husband. She doesn't look like anyone I've ever known. My sister thinks she looks like a koala bear. The heart murmur? The doctor told me about it shortly after Miranda's birth. He told me many children have them and they often disappear around school age.

Dr. Barrish measured Miranda's head. She measured it twice.

"I'm sorry," said Dr. Barrish. "Please take off your hat." She measured my head and said, "Average."

Miranda tried to open the door. Dr. Barrish told her to keep it closed, and Miranda frowned and began to cry. "She's gotten really sensitive when she's corrected," I said. "Especially when strangers correct her." I picked up Miranda and held her on my lap. Nearly naked, she seemed suddenly vulnerable. I shielded her in my arms.

I had already found out that Miranda fell in the 70th percentile for height and the 45th percentile for weight. But there was more. "Every child is special," Dr. Barrish said. "But there are several factors about Miranda that make me wonder if she might have a genetic syndrome."

I listened, stunned, while she elaborated. Any one of Miranda's special qualities might be insignificant alone, but together they could not be dismissed. The speech delay. The heart murmur. The long, tapering fingers. The unusually small head circumference.

Dr. Barrish handed me a tissue and I realized tears were spilling from my eyes. "I'm sorry," she said. "I know you've been blindsided. I know you thought this was just going to be a routine well-child check. I'd like you to mea-

sure your husband's head. If he has a small head, that might account for Miranda's. You could also look through your photo albums to find a relative Miranda resembles. Ask the grandparents. See if you can find an explanation for her unusual features. If you and your husband want to talk to me together, we can set up a time to meet. Or, if your husband has questions, he can call me."

Dr. Barrish told me other things, perhaps to soothe me. She said she has a large head. Her husband has a large head. Her children have large heads. Maybe she wanted to assure me that my family hadn't cornered the market on unusual head size. She told me she would set up an appointment with the pediatric cardiologist. Perhaps Miranda's murmur would just go away. Yet, if surgery were needed, it would be best to do it in childhood. She apologized again for delivering the shocking news the first time she met Miranda. "But it's in her best interest for us to know all we can while she's young."

I asked, "Does my gut feeling count for anything?"

"Of course."

"I think she's fine."

The time after the checkup was filled with dread and anger. I began obsessively eyeballing heads. At church, I could hardly attend to the sermon for examining the other parishioners. On walks, the landscape was of no interest. I was looking at pedestrians. "There's one," I'd say.

"One what?" my husband Bill would ask.

"A little head."

I measured Bill's head and found that it's slightly larger than average. "I was hoping you'd have a pinhead," I told him. He is so tall that from where I stand his head has a distant, possibly very small aspect. But, no. My son's head proved to be normal. In a breakthrough, my father-in-law admitted he can never find a ball cap that's small enough. And then, he and my mother-in-law, ever good sports, measured each other's heads and gave me the results by phone. With elation, I reported them to Dr. Barrish, who pronounced them "below average."

In a gesture of solidarity, my sister-in-law, who is no blood relation to Miranda, measured her head. It was below average, too. "And look at me," she said. "I'm of average intelligence and my small head hasn't held me back."

One day I found Miranda with my tape measure, measuring the heads of her dolls.

I had trouble sleeping. I made long-distance phone calls to my sisters and to my friend who is a doctor and a

mother. I was critical of Dr. Barrish and tried to make everyone discredit her to make myself feel better. I tried to make everyone, even those who had never met her, assure me that Miranda was normal.

My emotions had never been closer to the surface, poised for a chance to break out. When a woman in the library scolded Miranda for quarreling with her son, I was filled with both anger toward the woman and a fierce desire to protect Miranda. "You could have just let the kids work it out," I said. "Miranda, let's go." I started to cry in the library.

When an acquaintance asked, "How are you?" at playgroup, I had to excuse myself to weep in the bathroom. I began reading Laura Ingalls Wilder's books to my son and telling myself, "At least my family isn't starving. At least neither of my children has become blind. At least the grasshoppers haven't eaten all the crops." I saw a doctor of internal medicine for stomach pain and got a prescription for Tagamet. I started running longer and longer distances. I wanted to be numb.

"This is the test that scares me," I told Bill the morning we took Miranda to the cardiologist. "I can work with Miranda on speech, but I can't do anything for a heart."

The cardiologist was an elderly gentleman with bifocals and suspenders who earned my deepest gratitude because he spoke with great authority and—more importantly—he said what I wanted to hear. He said Miranda had an innocent murmur.

Bill and I told him why we had been referred by Dr. Barrish. My resentment was not well concealed, for he said to Miranda, "You were just fine until these doctors got hold of you, eh?"

Then he excused himself and came back a few minutes later with a woman he introduced as a geneticist. He had seen her in the hall and called her into the examining room for a consult. The geneticist's eyes were fixed on Miranda as her head was measured yet again by a convenient nurse. Her long, tapering fingers were fingered. Her scant speech was noted. I could see the woman tallying my daughter's fascinating features. She said she'd like to see Miranda again.

Dr. Barrish called me a few weeks later. The geneticist had contacted her. Miranda's facial features had reminded the geneticist of a specific genetic syndrome. If Bill and I agreed, Miranda's blood could be analyzed.

I asked the terrible, obvious questions. What kind of syndrome are we talking about here? One that involves early death and/or gradual deterioration? Dr. Barrish reassured me. This syndrome affected growth and learning.

I was torn. If we stuck Miranda in a category, would everyone treat her as the category instead of as an original, a wonder. I worried that we might be trading in Miranda and the limitless possibilities of her future for a diagnosis. In the end, Bill and I chose to have the tests done because of our somewhat shaky faith in the assumption that knowledge is power.

The meeting with the geneticists to discuss the results of the blood work followed a pattern that was to become all too familiar in our dealings with specialists. I would wait anxiously, trying not to hope that this expert would say, "A mistake has been made. Your child is absolutely normal." I steeled myself for the verdict, the definite pronouncement of Miranda's "condition," convinced that when I knew what was wrong I could do my best to fix it. Again and again, however, results were open-ended.

"We can't say she has a genetic syndrome," the doctors told us, "but we can't say she doesn't have one either." One geneticist asked if we had any concerns about Miranda, anything that struck us as being not quite normal.

Bill answered, "Since this all started, we can't look at Miranda and see *anything* normal." To me, this was the saddest, truest summation of that whole grim time.

I write this 2 years after Dr. Barrish's initial exam. I no longer resent her. She did what was right for Miranda. Had she not destroyed my peace of mind, I might never have taken Miranda on all those trips to the store, allowing her to handle everything as I named it for her. I might not have taught her colors using magnetic marbles or taught her the alphabet with letter-shaped cookies and sandpaper and puzzles. I might not have bought a pomegranate to expand her fruit horizons. I might not have taken a class in special education or read about learning styles, theories of intelligence, and learning disabilities. I might not be preparing myself for a life of advocacy—if not militancy.

Had it not been for Dr. Barrish, Miranda might not have the communication skills to continually amaze and delight us with her unique observations.

I watched from an adjoining room as Miranda was examined recently by an early childhood psychologist. During one portion of the test, the psychologist said, "Miranda, a boy grows up to be a man. What does a girl grow up to be?"

"A cowboy," Miranda answered with confidence.

Miranda does not resemble me. I could not have imagined anyone like her. As I have watched her blossom, I have come to realize that Miranda—not the geneticists, speech pathologists, or psychologists—will tell us who Miranda is.