

Small Wonder: Understanding My Daughter's Dwarfism

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The Dedmans knew their baby girl would be different from other kids. They didn't know how much she would inspire them.

By Margaret Dedman

An Amazing Girl

My daughter, Abigail, is a dwarf. Those words sound like a confession, but that's not the intention — they state a fact. Terms like "skeletal dysplasia" and "genetic mutation" are too intangible; words like "birth defect" seem downright cruel. My daughter has short limbs; she is a little person. From outward appearances, she's different, but her stature does not detract from who she is. If anything, it magnifies her presence. At 2, she has survived neurosurgery and has reshaped the perceptions of hundreds of people. And she's not even speaking in full sentences yet.

My pregnancy started out quite typically — lots of nausea in the beginning and some memorable bloating toward the end, with marked precious moments along the way: the first heartbeat, the first ultrasound, the first visible movement. All were treasured as my husband and I awaited our first child's arrival. We found out we were having a girl.

Complications, Reactions

At 32 weeks, our experience with all the normal events of pregnancy came to a screeching halt. My doctor scheduled an ultrasound to check our baby's position and found something else entirely. Abigail's arms and legs appeared shorter than normal, two to three weeks behind her head and chest.

Moments later, we found ourselves at Yale-New Haven's perinatal unit, greeted by a series of blurry faces we would come to know well — ultrasonographers, geneticists, the list went on.

It was here that we received the first piece of troubling news: Our baby's head and trunk were not in normal proportion to her arms and legs. That statement was followed by a cyclone of undecipherable words like "skeletal dysplasia" and "deviation from normal." Though the specialists had lots of words to throw at us, it would take two more weeks for us to find out what they all really meant: Our daughter was a dwarf.

We were devastated. I'd be lying if I didn't admit that on some level I we refused to believe it. Together, we struggled to accept a child who was different from what we'd thought she'd be. My husband's strength and optimism shone through quickly; he readily accepted the diagnosis. For me, it wasn't so easy. It took some self-pity and guilt before I dealt with the facts.

Imagine having an unborn child fail to meet your expectations — to be judging someone you don't know

based on their experience. It sounds so selfish.

What Is Dwarfism?

To weather the storm, we wrapped ourselves around every morsel of information we could find about dwarfism. It occurs in 1 out of 25,000 births, and there are more than 200 types; some are accompanied by serious mental and/or physical challenges beyond stature.

The most common type is achondroplasia, which is what our daughter has. In this condition, there is disproportional short stature — the head and trunk are of average size or larger, but the arms and legs are shortened, resulting in less-than-average height at every stage of development and markedly shorter stature in adulthood.

Achondroplasia does not affect intelligence; people with this condition can and do live healthy lives. And 85 percent of them are born to parents of average height. That fact still amazes us.

Abigail's Arrival

Abigail Louise came into the world on February 4, 2000. From the start we accepted her, as did our friends and family. Her appearance was a little shocking at first, mainly because we didn't know what to expect. We knew that she would have short limbs but we were surprised by the size and height of her head. But despite such surprises, she was met with loving, open arms.

Unfortunately, Abigail still had some medical battles to face. At Alfred I. duPont Hospital in Wilmington, Delaware, we learned that Abby also had coronal craniosynostosis, a completely unrelated but far more dire health issue than achondroplasia. Craniosynostosis is a condition in which the openings of the skull close prematurely. If left untreated, it can cause brain damage. Abby would need neurosurgery, plastic surgery, and a special craniofacial team to treat this illness.

But a week before her operation, the experts at duPont said they couldn't do it. Abigail's case was too complex. Too complex for the experts? How could that be?

Fortunately, we found some doctors at Yale-New Haven Hospital's Craniofacial Clinic who were willing to take us on. Abby's skull would need to be completely reconstructed — a challenging and difficult surgery. On the day of her operation, we watched as our 7-month-old daughter was wheeled away from us on a gurney.

It was excruciating, as were the six hours we spent in the waiting room, numbly thumbing through magazines and anxiously awaiting updates from the nurses. But our little girl came out of it with a new, improved skull and, most important, plenty of room for her brain to grow.

Abby's Future

Abigail's medical worries are behind her. But my husband and I still dread the day when Abby realizes she's a little person — not because it's a problem for us, but because we know she has to live and succeed in a big person's world. Everything from school desks to cars and restrooms are made for average-size people. We know that some days will be harder than other; elementary school is sure to include some taunting. And dating is likely to be a challenge, too.

But I believe God gives us what we need to handle personal challenges, and he was kind enough to give Abby an extra helping of charm and spirit. People gravitate toward her; they are engaged by her warmth, her exuberance. They smile when she looks at them.

"Special" sounds trite, but it applies. She is always laughing and often swaggers when she walks, a bit like John Wayne. And she doesn't just enter a room; she owns it.

What Average Means

Since Abby came into our lives, we've become a lot more philanthropic, joining a support group for little people and working to form another for families with children who have craniosynostosis. Our daughter has given us the strength we didn't think we had.

Abigail has taught us what normal and average really mean. These yardsticks by which so many of us (ourselves included) measure other people fall far too short. The madness behind established desired shapes and sizes from anything from breasts to toenails look very different from the vantage point of a child who is different.

Now that we've stumbled upon this revelation, we feel compelled to share it, to tell every person who comes into our path what dwarfism is and what it means: that little is different, but not less than, and that little people are just like the rest of us on the inside — the part that's really worth something.

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