



Ella Kinder

17. Mulch

By Julia Pewitt Kinder

I'M A DOCTOR so I know about Down syndrome.

If you are a parent of a child with Down syndrome, and you just took a nice long sip of coffee as you settled in to read this essay, then you now have coffee pooled in your mouth as it is impossible to swallow while laughing hysterically. Or perhaps you are drumming your fingers in irritation as you search for my contact information so you can tell me how little I really know.

But that was my first thought four years ago when I was told my baby girl has Down syndrome. I thought, “Well, at least I am a

doctor and I know about Down syndrome.” Ironically, Ella was born completely healthy. To this day, she hasn’t even had a single ear infection. Here I am equipped with my medical knowledge from four years of medical school, three years of residency, and several years in practice, and it doesn’t apply. In fact, many of the things I thought I knew about Down syndrome turned out to be false. It was as if “THE UNIVERSE” was determined that I would take a new road in life—and I would start my journey in the dark.

So there I was with a healthy baby who happened to have Down syndrome. I didn’t even realize that was possible. I had to refer to my medical books because I thought all babies with Down syndrome had heart issues or gastrointestinal abnormalities or some other problem in the long list of possible complications. In a strange way, I wished I could preoccupy myself with endless doctor’s appointments and medication schedules. If Ella had health problems, at least I would have a place to start. I would know what to do.

But all I had, it seemed, were questions: Would Ella crawl? Would she walk? Would we ever understand her speech if she even could talk? Could she learn to use the potty? Would she have friends? Would she go to a regular school? I assumed the answer to all these questions was probably *no*. I always said I would teach my child a second language, but I supposed I’d have to forget that. Violin lessons would have been nice, but I’d have to put that dream away, too. Ditto for my expectations that my child would go to college, drive, work, live independently, and get married. I felt as if I were hopelessly lost on a long and rocky trail. I didn’t have the provisions to get started, I dreaded the expedition, and I didn’t even know the destination.

Ella was not quite two years old when her Daddy decided to teach her some things about his job. He builds houses. First, he taught her about flooring. Within hours she knew the difference between hardwood, slate, and carpet floors in our house. Then they went outside to discuss brick, stone, and concrete. I was mildly irritated that he was wasting time teaching Ella worthless facts when she needed to learn other, more important things, like the letters of the alphabet and counting to ten. But then, a few days later, we were walking into a restaurant and she stopped and pointed at the ground around the

landscaping. “Mulch,” she identified, correctly. Mulch isn’t the most sophisticated of concepts, but it’s not a simple one either. I realized that if Ella at that young age could learn what mulch is, she would go on to learn a lot more than I’d given her credit for. With that one word, the path I was on suddenly became brightly lit with the warm sun.

Encouraged and excited, I returned to school: The School of Ella, seeking a degree in Down syndrome. I wanted to learn as much as I could so that I could give Ella every opportunity possible. In my Down syndrome coursework I’ve studied physical, occupational, speech, oral-motor, music, and developmental therapies. I’ve learned about early childhood development. I’ve learned to teach my child to read. I am practicing yoga. Slowly and painfully, I’m picking up some Spanish. Next week I start violin lessons. The more I learn, the more I realize there is to learn. And everything that I have learned, Ella has learned as well.

Every single night for the first two years of Ella’s life, I would go to her room to watch her sleep. I would look down at her and wonder, “Where is this terrible Down syndrome thing?” Ella was a child like any other child; she played, ate, and chased the cat. She had blue eyes and blonde hair and Down syndrome. It was only a small part of who she was; certainly not the most important thing. I had started out on this pilgrimage with the wrong questions. Instead of asking what Ella would *do*, I should have asked who she would *be*. My purpose along the way would be to provide the fertilizer for Ella to become who she wants to be. I could guide our family to our destination; a wonderful life. That was nothing to be afraid of.

I’ve been in Ella’s school for four years now and I am not even close to getting my degree. But I’m listening to what “THE UNIVERSE” was trying to tell me when I was placed on this new journey in life. It turns out that having a child with Down syndrome was never the problem. The problem was my fear of the unknown and my fear of the future. Through Ella, I’ve come to truly understand Down syndrome, and I want other doctors and medical students to know more so that they can inspire new parents of babies with Down syndrome. So I travel to medical conferences, schools, and hospitals and present lectures on prenatal testing, delivering the diagnosis, and

supporting new families. Most importantly, I try to erase the many myths and misconceptions of Down syndrome and provide current facts and optimism. I like to take Ella along, as my audiences are always more impressed with her than with her mom. She recently read the word “oscillate” to a neurologist. While that is a word to be proud of, I still prefer “mulch.” Not only does it stop weeds, it promotes the growth of some of the most beautiful things on earth.



Julia is a board-certified family practice physician, writer, and fitness instructor. She speaks nationwide on Down syndrome at medical schools, medical conferences, and hospitals. As a volunteer for the Down Syndrome Association of St. Louis, Julia offers new parent support and educates school children about Down syndrome. Currently, Julia is researching oral-motor therapy and its effects on orofacial posture and speech in children with Down syndrome.