

Contemplating Limits

Two Essays by Heather House

I think one of people's fears about having a child with special needs is that there will be (more) limitations on your life. And I would say that this is, indeed, the case.

The gap between what the boys are ready and able to do and what Fern is ready and able to do is widening. Sometimes it's her weight or strength or endurance that's the issue, but most often it's her height that's the limiting factor.

That was the case in the Oregon Dunes National Recreation Area, where we tried to rent a dune buggy to explore the dunes. Fern was too short for me to be allowed to take her and the boys out on my own. This ended up being a mixed blessing. Instead of touring by ourselves, we had to join a tour with a professional driver. We had the option of either taking the slower scenic tour or the fast adventurous tour. I told the clerk I needed a minute to talk to my kids about what they'd like to do but it was unanimous and they told they lady, "the fast one, definitely the fast one."



That's us in the back row. Lordy. This thing did up to 60 mph....on sand! We careened over the hills, slipping sideways on steep drop offs. Cypress and I were holding (sweaty) hands while Sylvan and Fern had their hands up in the air like they were on a roller coaster! I was terrified but the kids loved it! Much better than if I had driven them myself. So, you see? It works out. You just kind of have to roll with it. Control is an illusion anyway. ■

This child. She gets it in her head she's going to learn how to do something and she does not quit until she can do it. You need to know this: people who have Down syndrome set their own goals and can figure out how to achieve them. I did not know this for a long time.



The blisters on Fern's hands are from doing the monkey bars at school (she tells me she can do them the whole way on her own!) and the video is of the long-desired "trick" of hanging by her knees, which makes me VERY nervous. But what am I supposed to do? Tell her the doctors said she is hypotonic and therefore not likely to be as strong as her peers? Tell her that her neck might be compromised because of Ds and falling on it could be super bad? Tell her to stop chasing her dreams and be content sitting on the bench?

It took me awhile to realize that Fern is an athlete. She has a drive to master her physicality. I love that for her. But, man! When she careens down the hill on her bike or races her friends in the deep end of the pool, I am a nervous nelly. I'm constantly having to unlearn what I thought I knew about kids with Ds because there's Fern, right in front of me, doing the thing I was sure she couldn't do. ■

Editor's Note: These are two of ten essays the author shared with friends and family in October 2023, encouraging them to contribute to her daughter's Centre Region Down Syndrome Society Buddy Walk Team, "Fiddlehead's Fans." Indeed, they were in the top 10 Fundraising Teams.