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Not Ready, Not Ready

I am frightened that E is not ready to live in the nondisabled world. I fear that I wanted so much for her to cross over to that world that she will step out too soon and fall. I fear this every minute, then stop for a while, then fear it again, then stop. Catastrophe... breathe...calamity...breathe. What will befall her?

She has bad timing and like most disabled people whom I observe, illusive luck, the worst luck in the world in fact. It is as if the unfortunate card they drew at birth was not dark enough. I have noticed over 29 years that in their world one can not catch a break...ever.

This is what has kept me alert at 3 in the morning for 21 years. There is no expiration date on the "at risk child" apparently. Their ability to take risks like the rest of us can be permanently impeded by a natural state of already *being* at risk, like very few of us. I will never forgive her endocrinologist for letting that particular cat out of the bag. I am not at all sure I would have thought it up on my own or even made the connection to my daughter, had I heard the phrase "at risk child" out in the world. But when a professional uses it, it sticks.

My daughter and I have joked about our different tolerances for risk. High in the mountains, on a day's hike, I have been scared to death. She has been calm and exhilarated. If she is still "at risk" at age 30, then I, at 65, am beginning to feel we are now on the same playing field . She is braver, stronger, and younger. But because of her disabilities, she must work overtime just to carry on "normally" at risk or not.