

Meg with Ethan, now 14,
Savanna, 10, and Charlie, 11



a rare condition, a beautiful legacy

I'd dreaded the possibility that my kids would inherit my difference, but my love for them changed my perspective. **by MEG ZUCKER**

"WHAT did you say? Ectodumptily?"

I was in the final months of my senior year of college, at my doctor's office to get a physical so I could enter law school in the fall.

"No, Meg," the doctor told me. "Your hands and feet are like that due to a condition that's called ectrodactyly."

"It sounds like a type of dinosaur," I quipped.

Believe it or not, until that day I had no idea that my physical

difference even had a name. I was the first in my family to have only one finger on each hand, shortened forearms, and one toe on each foot. The doctors my parents had consulted both in the U.S. and abroad after I was born didn't know what to call it. Strangers assumed my mother must have taken thalidomide, a drug for morning sickness that was later found to cause severe birth defects. However, I thought that my differences were just a fluke caused

by a random mutation that would begin and end with me.

I never considered myself disabled. I grew up in a loving family, played the trombone and sang publicly, was surrounded by friends, and was selected for the Homecoming Court in college. Outwardly, I was determined to ignore my difference and expected everyone else to also. Underneath, though, I alternated between denial and self-loathing. I would shove my hands into my

pockets whenever a camera flashed or strangers extended their hand in greeting. When I graduated from college, my biggest fear wasn't about the poor job market but whether any man would be willing to marry me.

Most men were perfectly friendly but would usually place me in the "friend zone." When I met my husband, John, I was still focused on a recent breakup and doubted this new rebound relationship would go anywhere. To my surprise, not only did John commit for the long haul, but his parents and siblings offered us unhesitating support.

Although marrying John answered one crucial question, it didn't resolve my other big worry. Having a baby born like me would force me to face my lot in life and strip away the cloak of normalcy behind which I hid. I never knew for sure whether ectrodactyly was genetic until we saw a geneticist, who told us matter-of-factly that we had a 50-50 chance of having a baby with my condition. John reacted to the news as if it were something he'd always considered possible, but I was a complete mess.

Behind every birth defect is the question of "Why?" and not far behind that is "Who's to blame?" Even if John could forgive me, I was afraid that our child wouldn't. He would resent me. He would even hate me. In turn, I would hate myself. So I decided not to believe the doctor's grim odds, since none of my other relatives had the condition.

Getting pregnant wasn't easy. Yet after three miscarriages and an ectopic pregnancy, we finally got pregnant with our oldest child, Ethan. During my 20-week sonogram, I glanced at the screen and felt terror. Fighting tears, I peered at the tiny image with a single finger on each hand, and two toes on each foot. John gently put his arm around my shoulders as I began to digest the information. He spoke to the doctor,

* "When Ethan was born, my instinct was to keep him swaddled with his one-fingered hands covered."



Ethan inherited ectrodactyly, and almost three years later, Charlie was born with the condition. The next year, they welcomed sister Savanna.

but all I could hear were voices from my childhood: "Why do you look like that?" and "Why were you born with only one finger?" I thought my life was over. How could I raise a child who shared my disfigurement?

That was the irony.

When Ethan was born, my initial instinct was to keep him swaddled tight with his one-fingered hands covered. But it was late June, and he didn't like being wrapped in a warm blanket. So as passersby peeked at our baby, I had no choice but to let them stare and offer a strange smile. I realized that I had no reason to be ashamed of my son, and as time went on, I became incapable of it.

Once I let go of my fears about what others were thinking of him, something incredible happened, something exhilarating. It was like a personal seismic shift. I stopped hiding my own hands in public and even in pictures. Less than three years later, Ethan's younger brother, Charlie, was born. The fact that he shared our condition was no longer a terrible sentence in my eyes but something that would bond us. Seventeen months later, we adopted our daughter, Savanna, at birth. I hope that the positive impact of having a mother and brothers who have learned to truly accept themselves is a lesson that will serve her well too.

Over the years, I began to think beyond our own family's circumstances. Although our particular condition is rare, I knew that I could help other parents faced with raising children with differences. I started a nonprofit organization called Don't Hide It, Flaunt It, which works to advance understanding, tolerance, and respect. The condition that I passed on genetically feels like a gift to us now instead of a source of shame. By loving our sons, physical imperfections and all, I finally learned to love myself. 📍