

Excerpt from Growing Up Superheroes, The Extraordinary Adventures of Deiblia Nye Copyright © 2015 by Diane Fraser

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On the Fence, 1983

My sister's baby crashed into the world three weeks early, on December 17, 1983. Our mom arrived at the hospital just in time to see her newborn granddaughter before they took her away for emergency surgery. "Her fists were pumping, she was screaming, her heart and lungs are good. She's a fighter," Mom said. But Deihlia was born with spina bifida. She had a lump of tissue on her lower back where the nerve endings of her spinal cord tangled together abruptly. That wasn't all - her abdomen was wide open. Organs were on the outside of her body, she had one tenth of the intestines she should have, and she had no bladder. In the midst of the turmoil, my sister Donna's husband Linc named her Deihlia, an old family name from deep in his family's past.

Deihlia required immediate surgery, and the best surgeon was seventy-five miles north, in Boston. Donna's doctor was apologetic, distraught, and deeply upset. We'd had a feeling something was wrong during her pregnancy, and when she talked to him about it, he assured her everything was ok. No tests, no worries. Shock, confusion, chaos. Welcome to the world, little star.

My sister Donna was nineteen, two years younger than me. She'd gotten married at seventeen, moved to Cape Cod with her husband Linc, who was twenty-seven, and less than a year later she became pregnant with Deihlia. As the baby grew inside her, we became closer. My mother and I gathered around her to build bridges for her and the child she was bringing into our family. A new life was entering ours. Donna was so young and going through something very adult - carrying a child for almost nine months then having her taken away almost immediately, after a brief and tumultuous hello.

We learned that spina bifida is a condition that begins in utero, with abnormal growth of the spinal column. Sometimes it affects not just the child's body, but also their brain. The condition has a range of expressions, from mild to severe. Deihlia had the most severe form since her spinal cord ended in a lump on her lower back, leading to paralysis. It wasn't yet clear if it had affected her brain. The condition had many other possible complications, including one in which the brainstem and cerebellum extend down into the neck, causing multiple problems, such as choking, breathing problems, and swallowing issues. We were also told that the reverse can happen - the brainstem can push up into the brain and cause brain damage. It was too soon to know how it would affect Deihlia.

How did this happen? Donna's pediatrician told us that only one half of one percent of babies born each year are born with spina bifida. It could be genetic, environmental, or due to lack of folic acid in the mother. There was no way to know for sure *why* it happened, but we had to prepare ourselves, as much as we could, for whatever else was *going* to happen.

I felt like a coward. I was afraid to meet her, knowing I'd fall for her, afraid to love her then lose her. There was no time to waver. No time to adjust, to think, to plan, to recover, to pray, to be held, to hold, to connect. There was no time. She wasn't going to make it. They had to bring her to Suffolk Universal Hospital in Boston. The ambulance was waiting. Surgery the next day lasted seventeen hours. We were all there: Donna, Linc, our mother, and me. It was the longest day of our lives. All the surgeon could do was get in there and figure it out as she went along. She couldn't explain everything she had to do.

Deihlia died once that day in surgery. She was clinically dead according to the surgeon in charge and they brought her back. She was a strong heart in a small, unfinished body. The next day came and it was the same thing: another seventeen hours in surgery and another death. But the surgical team did it again, pulling her back into a body that wasn't equipped to hold her.

We sat in the waiting room. Metal chairs with faded light blue cushions were crowded together in a small, windowless area off the main hallway. Tattered magazines that had been read and re-read lay in loose, shiny piles on the small tables, their seams worn and coming undone, pages slipping out. The dry air felt like it contained the held breath of the hundreds of parents who'd waited in the small, cramped space for their children to get through surgery. We were the only people in there that day,

and we were tense, scared, and overwhelmed. Lightning had struck our lives, and we had no idea how completely our world had changed.

Linc was restless. He had a hard time sitting still before this happened, but this put him over the edge: his daughter on an operating table, the small waiting room, his young wife distraught and overwhelmed, and the helplessness. More than anything, it was the helplessness. "I need to go for a walk," he said, his wiry body jumping up suddenly. He ran his hand through his short, light-brown hair as if he could pull the situation out of it. "You stay here. I'll be back in a bit," he said. Donna looked up at him and nodded, her large cheekbones stood out against her dark, wavy, shoulder length hair. Her face was still pink from giving birth the day before. Linc grabbed his brown leather bomber jacket off the back of the chair and shoved one arm into a sleeve as he left the room.

As we sat and waited, something appeared in the doorway like a mist. Like static or a light shadow, it came towards us, becoming more solid the closer it got. Then he was there - a kindly looking old guy in a light blue bus-driver's uniform. My sister didn't notice him. She continued to thumb through the magazines she held in her lap. He sat down across from me in the small space, resting his elbows on his knees. He looked directly at me, keeping his eyes on mine. Was he trying to tell me something? Who was he? What was he doing here? He nodded his head slightly, as if we'd just been introduced.

Then I understood. He wasn't the ghoulish skull-faced creature from movies, this Death. He was more like a regular working guy doing his job, keeping watch over a possibility. I kept my eyes on him, it seemed important to acknowledge his presence. Was he going to carry Deihlia out of the hospital that day? I memorized his uniform: the breast pocket, the crease down the center of his slacks, the sturdy no-nonsense black shoes. I looked over at my sister, getting ready to say something to her. He shook his head no.

A little while later, Deihlia's surgeon Dr. Zee stepped purposefully into the room, her face grave. A tall, hearty woman with short black hair peppered with gray, she started to speak with her hands out, stretching them away from each other like an invisible game of cat's cradle. Then she paused, keeping her fingers wide and open like something fragile rested between them. "She won't live the week," she said, looking first at my sister, then at her husband Linc. "You need to make a decision. If she dies a third time in surgery, should we resuscitate her again, or let her go?" We stared at each other with hollowed-out faces, the precarious enormity of Deihlia's life was something we couldn't grasp, let go, or hold.

Deihlia. Would she know more than these two days of life?

Hello, I Love You

Even if Deihlia was only going to be with us for a short while, I wanted to know her. I'd never been in a neonatal intensive care unit before. Walking by the cribs where each critical infant lay, hooked up to monitors, with liquids hanging in IV drips, tubes for input and output, dressings, nurses checking and adjusting them made me hold my breath - beeps, the hush of controlled air, sedation. With half of her body in a cast, she was like a cute little bug with tubes and wires here, there, and everywhere. Delicate and strong. Donna and I stood next to her crib. We could touch her arms, her face, her hands.

We wanted her here, on Earth. It was a lot to ask of her.

Looking down at her in the crib, the axis of my world shifted. Some things dropped away, and others rose up out of the darkness. Here was Deihlia - a tiny little being, a fighter, part of my family, part of us. What was she doing here, coming in like that? Whatever it was, we now had a team. Team Deihlia. How long would we have with her? Her surgeon said that if she survived she'd require many, many surgeries. We had to prepare for her probable death. There was nothing to rest on, there was no false hope. There was today, and more surgery tomorrow. All we could do was be there, stand by her, love her - and pray.

Up until then, babies born with complex conditions such as hers didn't survive. They lived a couple of days, maybe a week. Dr. Zee was advancing pediatric surgery in profound ways, but we didn't know that then. We didn't know anything about her in those first few days, but that's who Deihlia got. Deihlia wasn't born in a country or area with limited medical care. That was the first stroke of luck: she was born near Boston, where we have excellent, world-class medicine. The second stroke of luck was her surgeon, who took not only an interest in her case, but who also had the ambition, skill, and courage to handle it. Soul mates come in many forms. There was only one thing we did know for sure then. We knew that we loved Deihlia and we were in it with her, wherever it was taking us. That was the third stroke of luck: love with commitment. Or maybe that was really the first one, after all.

Christmas came up fast a few days later. Donna and I drove through deserted Boston streets on our way to spend it with Deihlia at the hospital. The brownstones on Commonwealth Ave were sleepy, blinking at us as we drove by and disturbed their holiday slumber. On Boston Common, lights strung on trees blew in the winter wind like party decorations someone forgot to take down. There was no one on the sidewalks, no cars in the streets. We had Boston all to ourselves as we made our way to the hospital. Silver garland hung in the halls on the ward. There, we stood by Deihlia's crib, holding her small hand and looking at her. Saying a few words here and there, telling her about us, telling her her name - Deihlia - trying to conjure a future outside of the hospital walls. Saying I love you.

The Center

The winter and spring after Deihlia's birth went by in a chaotic blur. Deihlia's prognosis wasn't good. "Have another child," the doctors told Donna and Linc, as if another child would soften the blow of losing Deihlia. She was a part of our family and looked like her Dad, with his blonde hair and small nose; her mischievous grin. She had presence. Some of the surgeries she had to have were so complicated, the recoveries so long and arduous, the potential for her to die was extremely real. I wouldn't see it, couldn't see it, refused, though sometimes the Bus Driver would shimmer into the room, then stand quietly in the corner with his hands in his pockets, joining our vigil.

Deihlia was three weeks premature. She had water on the brain from her spinal condition, so they put a shunt into her head to help it drain. She had seizures. Every day was a rollercoaster ride of medical issues and emergencies. During one of the surgeries, the surgeon had to make a bladder for Deihlia, using pieces of her intestine. They had to take skin from the lump on her back to cover her abdomen. They gave her a colostomy. There was no other way, not with her intestines being too short. Every surgery was critical to her survival. She was so tiny, just a little premature baby. How did they do all of that inside her? There were long periods of not being able to hold her, show her things, rock her to sleep, take her out. More than anything, we wanted her to live, to survive. That was our prayer.

From home to the hospital and back again, my sister Donna went from being a scared, mixed-up nineteen year old to a tenacious mother bear. She did it pretty quickly, getting her driver's license and triumphing over the gnarled Boston streets. It was a lot to navigate – the medical system, the emergencies, Deihlia's unique body, the extensive planning for "maybe." - then always, always having to change plans because of the surgeries and their aftermath.

Deihlia was still with us, the center of our lives. Someone wise and playful looked out of her eyes, but kind of held back. Just checking things out, she was non-committal. I understood why. We all did. We wanted to give her everything we could, with no guarantee for tomorrow. As she passed the eighth month mark, she was tentative, exploring things, opening up slowly. The shunt was removed. The seizures stopped. When her body was healed enough, her mom let her crawl around on the floor. For her, that meant using her arms and elbows to pull the bottom half of her body along. She wanted to explore everything; she was starting to get interested in life. There were adventures to be had in the kitchen, on the porch, over there. She wanted to have fun, she wanted to know. But food was an issue – it was hard getting enough nutrition into her, combined with her medicine and the antibiotics. She had so much streaming through her fragile sewn-together system. She didn't have much of an appetite for food, but she was developing one for life.

People would avert their eyes when they'd watch her crawling and realize that she was paralyzed from the waist down. Some couldn't bear to look. For others, it was simply a politeness - not staring. But Deihlia got the right Mom when she crashed into this world. As a kid, my sister's neighborhood nickname was Chimp. At eight, she climbed a neighbor's chimney barefoot in her shorts, t-shirt, and dark braids, then waved at the teenage boy next door through his second floor bedroom window as she hung on to the chimney stones outside with the other hand. Sitting at his desk doing homework, he jumped when he saw her smiling and waving outside. She was always out riding her bike, climbing, playing games, getting her school dress dirty. I was the bookish artist, holed up in our bedroom drawing, reading, writing stories, and putting together outfits as I wished for magic powers that would turn me into someone with a different life.

Donna was always very physically active and she was going to help Deihlia be physically active, too. She let her scrape and bruise along the floor, her knees thumping and banging behind her. I was more cautious, trying to keep her from harm. Deihlia would grin and look back at me over her shoulder as she scuttled off like a mermaid child across the linoleum, chasing the cat. Donna would tell me to let her go. "Just let her be a kid," she'd say to me, watching as Deihlia went off into the other room. I

held my breath, giving her a few paces before I chased after her. My sister was still a kid, only nineteen. We both were. In a way, we were all kids.

It was just the four of us for her first birthday. Miraculously, she was home and not in the hospital. My sister baked a big round cake. Linc came in, waiting for the candles to be lit, and paced around the kitchen. Deihlia only ate a couple of bites, but she wore it, chocolate frosting smeared around her mouth, just like other one year olds. It was her birthday. She'd made it a year, fifty-one weeks longer than they'd given her. I ate a big piece of cake, wide awake, taking her in.

