

A photograph of three hands holding a thick, braided rope against a blue background. The top hand is a woman's hand with red nail polish. The middle and bottom hands are younger, possibly children's, hands. The rope is held taut, running vertically down the center of the frame.

Eight Fingers and Eight Toes

Accepting Life's Challenges

Debbie Jorde

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Columbine Press

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Some names have been changed to protect privacy.

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Dedicated to my loving husband, Lynn, and my amazing children, Heather and Logan.

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As I thought about all that I've learned from being Heather and Logan's mother, I realized that I didn't want to die one day and have all the valuable lessons die with me. So I wrote my story, partly from memory and partly as events were happening. When I completed the first draft, I asked a few people to read my manuscript and offer feedback. Some of my readers were anonymous, but I would like to thank the readers I know--my beautiful daughter, Heather Madsen, not only shared her experiences and contributed her insightful writings, but read and edited each draft; my sister, Kathy Cherrett, read the first manuscript from start to finish and supported me through the book's completion; my sister, Shelli Lether, not only supported my book from start to finish, but validated and honored me by viewing me as her role model and teacher; my friend, Kathy Newton, whose praise and support helped me believe in my ability to write the book. She gave feedback throughout the process and edited the final proof for errors. Kathy also gave my manuscript to Annette Haws, an English teacher, who edited and made helpful suggestions. Thank you Carolyn Green and Sara Brozovsky for editing.

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My story would not have been published without understanding, insights and encouragement from my creative and witty son, Logan Madsen. The theme and design for the cover of the book are Logan's ideas and he shot the photos for the cover and for some interior pictures. Logan is an artist www.loganmadsenfineart.com. He paints with acrylics and oils, has an associate degree in graphic design and has an artistic eye with photography.

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I would also like to thank the staff at the University of Utah Behavioral Home Program for the excellent medical care they give to Heather and Logan.

A heartfelt thanks to all my customers and my good friends. Your support through life's many challenges over the past thirty-five years has been invaluable. My gratitude also goes to the many people who have supported me and touched my life, but whose names are not mentioned here.

I've had many experiences to share with limited space in which to include them. In choosing the stories I've included, I've left out others. All the people involved in this story would tell something different from what I have chosen. One day, I hope Heather and Logan will tell their own stories. Responsibility for errors or omissions is mine. If I have misrepresented anyone in any way, I apologize. For the sake of privacy, I changed many names.

Eight Fingers and Eight Toes

Accepting Life's Challenges

FOREWORD

“They have disabilities, but they are not their disabilities.”

When Debbie Jorde asked me to write the foreword to “Eight Fingers and Eight Toes: Accepting Life’s Challenges,” I was truly honored and humbled. I had known Debbie for almost three decades, having met her shortly after my arrival at the University of Utah as a junior faculty member and just after the birth of Logan, the second of her two children with Miller syndrome. This condition, named for the author who first published a description of the syndrome (which is also referred to as postaxial acrofacial dysostosis), consists of birth defects of the face and limbs. It is a very rare disease, with only about 30 individuals documented in the entire medical literature.

At the time of Logan’s birth, one of my colleagues, a medical geneticist, was caring for Logan’s older sister, Heather. When Logan was admitted to Primary Children’s Hospital as an infant, my colleague invited me to “take a look” at him. As a young and recently trained clinical geneticist, I reviewed the medical chart and appreciated the experience of seeing a child with this rare syndrome. Soon thereafter, I was introduced to Debbie, and I was immediately struck by her poise and composure. I wondered how she – as the mother of two children with this rare, poorly understood, and visibly obvious syndrome – was really coping. Over the ensuing 10 years I would run into Debbie at the Children’s Hospital with Heather, Logan, or both, as she orchestrated, in her words, the “maze” of specialists’ visits.

Years later Debbie met and married Lynn Jorde, another long-time associate of mine, and I recall the happiness I felt that two people whom I admired were together. Afterwards, at University social events, I would greet Debbie with Lynn and receive updates about Heather and Logan.

On one occasion I attended a talk that Debbie delivered to the first-year medical students, relating her story of raising two children with this medically overwhelming condition. Later, with my clinician’s tape recorder in place, I reflected on my impression of a mother who had accomplished so much: rearing her children with this rare disease as a single parent and coping well with its many complications.

Then I read “Eight Fingers and Eight Toes ...”

Throughout the pages I was struck with how little we as physicians (and, I am certain, other health professionals) are in touch with the actual lives and day-to-day stories of our patients and their families. We provide “news” of the diagnosis, we obtain snapshots of progress at clinic visits, we talk among ourselves about “coping,” “acceptance,” “feelings,” maybe even “celebrating differences” -- all noble themes -- but do we really *know*? Perusing this narrative taught me that we do not. We intellectualize about so-called narrative medicine, we theorize about a parent’s (or “patient’s”) coping mechanisms, we try to be in “their shoes,” we even strive to empathize--all with good intentions-- but we don’t really know: we only observe the surface layer.

Debbie Jorde has created a masterful piece that exemplifies what is now an emerging genre: parents telling the story of their children and family, not as an anthropologist investigating a medical culture or as a counseling student performing a qualitative study, but rather through their own unique lens. In “Eight Finger and Toes: Accepting Life’s Challenges,” we witness and experience the true-to-life account of how one deals with seemingly endless challenges: the news of the birth of an infant whose condition is highly visible but poorly

understood, the chronic medical problems requiring many surgeries and regular visits to multiple specialists, and the existential dilemma--the assault on the meaning and essence of parenthood--of the condition's genetic nature. And while these are the centerpieces of the story, the edges of the account--the outer rim of its circle--include divorce, single motherhood, an eating disorder, a chronic lung disorder in Heather and Logan (that mimicked cystic fibrosis and is not even a typical component of Miller syndrome), depression, and autism spectrum disorder. From this emerges resilience, self-doubt, inspiration, pain, authenticity, trials, self-esteem, differences, creativity, wisdom, and real quality in life: not simply "accepting" life's challenges but embracing them.

The story "Eight Fingers and Eight Toes..." has not concluded; life proceeds for Debbie, Heather and Logan. We read the story, are touched much of the time, inspired most of the time, ponder the events all of the time, but meanwhile "life's challenges" continue while we are reading these words.

The story's postscript and our understanding of Miller syndrome was enriched recently by the identification of the gene that, when mutated, causes the syndrome. Researchers at the University of Washington, the University of Utah, and other institutions published articles characterizing the gene discovery in the prestigious scientific journals, *Nature Genetics* and *Science*, in 2010. One of the insights provided by the research, which brought some clarity to Heather, Logan and Debbie, was the discovery that they had changes in two very different genes: the recently discovered Miller syndrome gene and alterations of a completely separate gene for lung disease. This explained their unusual chronic lung disease, which is not a typical feature of Miller syndrome.

"Eight Fingers and Eight Toes ..." should be read by all who care for persons with medically complex and rare conditions. While it covers many themes, the book's most stirring message is captured in Debbie's own words in Chapter 12: "They have disabilities, but they are not their disabilities."

John C. Carey, MD, MPH
Professor and Vice-Chair,
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PHOTOS

- Heather, 2 weeks old, having her first bath at home, 1977.....
- Heather, 9 months old, 1977.....
- Heather, 3 yrs old, with her brother Logan, 6 months old, 1980.....
- Heather, 6 yrs old, with Logan, 3 yrs old, 1983.....
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- Heather, 33 yrs old, placing her forearm in her mother's palm, 2010.....
- Heather, 33 yrs old, writing, 2010
- Heather, 33 yrs old, typing on a computer keyboard, 2010.....

Chapter 1

My first baby was finally coming. The large round mirror mounted on the ceiling of the delivery room was positioned at a perfect angle to give me a good view of the birth. At this time ultrasounds were not routinely performed, so we had no idea of the baby's gender or health. As my husband, Terry, sat next to me, I was filled with anticipation and curiosity, wondering whether we would have a boy or girl, imagining which of us the baby would resemble.

Outside, the Utah landscape was white and pristine with last night's snow, but inside the hospital, the world was a sea of stainless steel and blue-green surgical scrubs. The room pulsed with a sense of excitement.

I looked at Terry, whose face revealed his own expectancy and wonder, and then back at the mirror.

As the baby pushed out of my body, I spotted the crown. The swatch of dark hair pleased me; it meant that my baby wasn't bald. The presence or absence of hair seems a small matter now, but I was young and naive. Nothing in my experience as a twenty year old woman had prepared me for the reality of what was to come.

When the baby's head emerged, the doctor used a small suctioning bulb to remove fluids from its nose and mouth. I wasn't worried: This was a routine procedure performed on newborns. Besides, Dr. Kirk had been delivering babies for many years; he had delivered my brother, Cloyd, eighteen years earlier.

When he finished suctioning, he helped ease the baby's shoulders out. Once freed, the rest of the body slid out, wet and slippery, and the doctor exclaimed, "You have a girl!"

Terry leaned closer and squeezed my hand. I wasn't worried that he might be disappointed not to have a boy. Throughout my pregnancy, whenever he was asked if he wanted a boy or a girl, he had responded that it didn't matter as long as the baby had ten fingers and ten toes.

Suddenly my eyes caught sight of our baby's body. She looked strange to me, nothing like I expected. Her skin was a pale blue and coated with a creamy substance. Was that normal? My eyes flashed to Terry, whose brown eyes revealed his own uncertainty. My eyes quickly darted to Dr. Kirk, but his focused expression revealed little. My attention finally settled back to my daughter.

She didn't seem to be moving. I was frightened. Was she alive? Panic coursed through me. I had heard the term stillborn before, but had never imagined that something could go wrong with my baby. I was young and healthy. So was Terry. Nothing could be wrong with our child, could it?

As the doctor placed the baby on my abdomen, her body flopped like a rag doll. Was she breathing? I couldn't tell. My heart pounded wildly inside my chest.

A pair of nurses moved nearby, but my attention was focused on my small motionless baby and the doctor who was busy clearing more fluids from her nose, mouth and throat. The word breathe was like a chant inside my head: Breathe, breathe, breathe.

Finally, after long and excruciating moments, gurgling sounds arose from her mouth. She made noises that sounded like muffled cries. Her arms and legs moved frantically, as if she had the sensation of falling. Yes! She was very much alive. I was relieved. My eyes moistened with tears.

And then I saw her arms; really saw her arms.

Something was wrong. These were not normal arms; not normal hands.

Now I was the one struggling to breathe.

My pulse raced as I tried to make sense of what I was seeing. Her small bluish arms looked abnormally short and were severely bent at the wrists. Her hands and fingers looked really small--too small even for a newborn.

Just as quickly as my eyes absorbed the images, my mind worked to deny them. This wasn't supposed to happen, not to us. My mind raced. Her arms were fine. She had simply been cramped inside the birth canal, she would look differently in a few hours; she just needed a little time in a less confined space. What else could explain her odd appearance? Nothing was wrong with my baby. She was normal. She had to be. I had to make my denial real. I whispered out loud, "No, her arms aren't bent,"

I blinked to clear my vision, but that did nothing to correct the distorted arms on my baby's body. A lump was forming in my throat. I could feel the muscles in my face strain from the fear and worry that consumed me. My voice was like a prayer inside my mind: "Oh please, let her arms be all right. This can't be happening. This isn't real. I need to know that what I'm seeing isn't the truth."

And then I heard Terry's voice. "Something's wrong with her arms," he said. The certainty in his voice hit me like a fist.

At that moment, I knew that what I thought I was seeing was true. Those words reverberated inside my head: Something's wrong with her arms.

"Is everything else all right? I mean, besides her arms?" I asked. I barely managed to form the words, but I needed some kind of reassurance, some good news.

Dr. Kirk, who was in his sixties and had undoubtedly comforted other new mothers in difficult situations, placed his hand gently on my shoulder. The expression on his lined, porous face softened as he spoke. "Well, Debbie, this isn't the kind of baby I anticipated for you."

My heart sank. This wasn't the kind of baby I had anticipated either.

Chapter 2

Our baby had eight fingers and eight toes. Not ten. Eight.

As I gazed at her deformed arms and hands, all I knew was that I wanted to leave the delivery room and pretend that I hadn't given birth, not to her, not to a baby like this. I wanted to start all over. I told myself that I would just go home and get pregnant again.

I would have a different baby. I didn't want this one.

After the birth, Dr. Kirk took the baby to another area to examine her. A nurse wheeled me into the recovery room and took care of me, cleansing my body and dressing me in a fresh gown.

Terry had left my side briefly to telephone his parents, but returned a short time later. As he sat next to me, I stared at the ceiling and wondered what to say, what to do. I was afraid to put my feelings into words. I didn't know how Terry would respond if I admitted the truth. How would he react if I said out loud that I didn't want the baby? Would he be hurt? Angry? I wasn't sure. This was his child, too. I studied his face for clues and saw the same stunned and confused expression I'd seen in the delivery room when he'd first noticed her arms.

Finally, I found the courage to say what I was feeling. "I don't think I want this baby."

"I don't either," he replied, his voice sounding tense. "What are we going to do?"

I didn't have an answer, at least not a practical one. I wanted to get dressed and leave the hospital. I wanted to pretend that this had only been a bad dream. I knew we couldn't just walk away, but I wanted to go far away from this hospital.

None of this was supposed to be happening. It had all started out so differently.

Approximately four months before the wedding, I had been late for my monthly cycle. That coupled with recent bouts of nausea prompted fears that I might be pregnant. I couldn't get my mind off of the changes that were happening to my body. I kept trying to deny the evidence because I didn't want to be pregnant, not yet. That only happened to other girls, not to me. I continued to look and hope for physical signs that my suspicions were wrong, and every day I was disappointed.

Finally, six or seven weeks later, I had to know the truth. I had made an appointment with a doctor to have the necessary tests done to find out if my suspicions were correct. I was so scared. I timidly walked into the doctor's office and checked in. I felt like I didn't belong there. I sat down and looked around the room at all the pregnant women. I couldn't believe I was there. I opened a magazine, only to shut it again. I got up and paced around the small, plain office and then sat down again. At last, the nurse called my name. My heart jumped as I rose and walked to the office.

The nurse drew my blood and excused me to the waiting area to wait for the results. I looked at the clock; the black hands seemed frozen, as if time had stopped. How long would I have to wait? A woman seated nearby cradled her bulging abdomen. I kept looking for magazines to read to take my mind off what was happening and why I was there, but all the magazines had something to do with pregnancy or motherhood. I wanted to run. Would this ever end? The nurse called my name again and I walked to the desk. My knees trembled.

"The test is positive. You are pregnant," the nurse said, her voice as flat and steady as rain.

I scheduled a future appointment and left the doctor's office in a daze. Overhead the sun broke through dismal clouds.

As I drove away from the narrow brown building, I considered the life growing inside me. "Are you really in there?" I asked and patted my abdomen. I was afraid and filled with disbelief, but at the same time, I felt the first twinges of maternal love. When I thought about telling Terry the news, I wondered what I was going to say. I wondered even more about how he might react to the news. Neither of us had counted on this.

I fought the urge to call him. Instead, I waited until later in the evening when we were alone. "I went to the doctor today and found out that I'm pregnant."

There, I had said it.

Silence.

"Well? What do you think?"

"What is there to think?" he said, and shrugged his shoulders.

Neither of us seemed to know what to say. I had the whole day to begin getting used to our new reality, but the news was fresh for him, and he seemed dazed, as I had been earlier.

"Well, I'm glad that we already set our wedding date, so people can't say that we had to get married." I was worried about what people would think of me. "Let's not tell anyone until after the wedding."

We kept our secret. After our wedding, I continued working at the hair salon as a licensed cosmetologist. Eventually, I started growing out of my clothes. The time came to announce that we were expecting. I cut words out of the newspaper and pasted them in a card to make the sentence: "We are going to have a baby." I passed the letter around at a family gathering. Everyone was very happy for us.

How did our beautiful dream become a nightmare? How could a baby like this belong to Terry and me?

A short time after the delivery, an orderly wheeled me into a room in the maternity ward. Overhead the florescent lights seemed harsh and unkind. I felt like a stranger in my own life. None of this was supposed to happen to us.

When we arrived in the small room, Terry's parents were standing there, waiting for us. They both smiled, trying their best to be optimistic and reassuring. They hugged Terry and leaned to kiss me on the cheek.

The sky in the window was dark and starless. I could have stared into the void for hours. I didn't feel like talking.

After a few awkward moments when none of us seemed to know what to say, Terry's father finally spoke. "You have to remember there's a perfect spirit inside that little body," he said. His wife nodded and took the seat Terry offered.

Terry's parents were devout Mormons, and I knew those words were intended to comfort and reassure me. Instead I felt ashamed. I, too, had been raised a Mormon, but I rarely attended church anymore and believed I had disappointed everyone by becoming pregnant before marriage. I also knew what our church taught about children with disabilities, and how the parents of such children were chosen by God. I knew, too, that a mother's love was supposed to be unconditional. What kind of mother doesn't want her own child?

I tried to force a smile, but even that was too much effort. I could not accept that the baby in the delivery room belonged to me. I didn't want to hear about her perfect soul. I didn't want to hear about her at all.

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