Why Did I Have to Be Born with Cerebral Palsy? | CPD

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Gabriel gets a little help from his brother, Christopher

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March 25 is National Cerebral Palsy Awareness Day. Cerebral Palsy is an umbrella term for a number of non-progressive, non-genetic, non-communicative disorders that affect a person’s movement and muscle control. According to United Cerebral Palsy, there are 800,000 people living with CP in the United States, and an additional 10,000 babies born each year will eventually be diagnosed with CP. My son Gabriel was one of the 10,000 babies born in 2007. He and his identical twin brother, Christopher, were born 10 weeks premature because of complications from a Twin-To-Twin Transfusion Syndrome pregnancy. In February 2015, Gabriel asked me a question that I knew we’d have to face some day, but I wasn’t prepared for it yet. In a fit of frustration, he stomped his foot and said, “Why did I have to be born with Cerebral Palsy?” I had no response at the time, so I’ve written the following letter for the next time I have to answer him.

Dear Gabriel,

You asked, “Why did I have to be born with Cerebral Palsy?” And my simple answer is, “I don’t know.” I can tell you that you had several risk factors, including being born too early, surviving as the recipient twin from a Twin-To-Twin Transfusion Syndrome pregnancy, struggling to breath after you were born and needing a ventilator, taking in multiple blood transfusions, and enduring multiple infections while you were in the NICU. I can tell you all of these things, but they still don’t answer the question.

May I, instead, answer, “What does having Cerebral Palsy mean for me?” My answer is, “Everything and nothing all at once.”

I answer “everything” because it’s what the people who stop you in the grocery store see first. The people who constantly exclaim, “Wow, he can move fast on that thing!” as you try to roll your walker around them because they’re standing in front of your favorite cereal; they’re the same people who ask, “What’s wrong with him?” What they never see, though, is you fighting to roll over, crawl, stand, walk, and talk and defying everyone’s expectations for you. The therapist who told me you’d never play basketball and the doctor who told me you might never read or speak were both wrong.

You have overcome every goal set before you, and you continue to do so. When faced with a challenge, you sit by yourself and you practice, slowly, laboriously, and completely independently. Those of us who have watched you take a problem off to a corner and return with a solution after hours of frustrating work have admired your independence and persistence. You continue achieving goals and proving all of your supporters right and every naysayer wrong.

Gabriel and Christopher giggle their way through a family outing.

However, remember that you are no one’s inspiration but your own. Let others admire your accomplishments, but remember that they are yours and no one else’s. Your life is amazing not because you have Cerebral Palsy. It’s just amazing because you are you.
This is why I say that CP is nothing. CP didn't give you your sense of humor, which causes you to break out in uncontrollable giggles several times a day. It didn’t teach you to love music with an intense passion that sometimes translates into the rest of us hearing the same song 10,000 times in a row as you memorize the words and tune. It didn’t give you the creativity that allows you to build stories with Christopher, complete with theme music and special dances for each story. CP has nothing to do with your smile, or the way you cry when you find things beautiful, or the way that you try to make Christopher feel better when he’s upset. CP doesn’t keep you from rolling your walker into the lake when you want to go for a swim, nor does it keep you from going on hikes and playing with your brother on swings and playgrounds.

I know that you will ask, “Why did I have to born with CP?” several more times as you go through life, and that’s OK. I’ll be here to sit with you, give you a hug, and cry with you. On those days that CP seems like it’s everything, remember that it has nothing to do with who you are and who you will become.

Love,

Mom