



Stories For An Unborn Son

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It began with a hiccup as one cell tried to transfer its data to another. It began long before I, your mother, was born. A gene mutation, carried invisibly by women and passed to sons, snakes through our family tree. It is a fragment of history we can trace, a tiny bundle of stories floating in our blood.

In males the primary symptoms of this genetic condition — hypohidrotic ectodermal dysplasia, or HED — are sparse hair, peg- or cone-shaped teeth, and the inability to sweat. At every moment, a normal human body engages in a struggle against death from overheating, releasing at least a quart of perspiration a day and up to several gallons in extreme conditions. But a body without sweat glands flies on faith.

The secondary traits of HED include certain distinctive facial features, such as dark circles around the eyes and a saddle-nose deformity: a deep depression in the bridge of the nose. Sufferers have trouble breathing, so they have trouble sleeping, and in turn they have trouble staying awake. Because of their hollow-eyed appearance and sallow skin, they look ill

even when they feel fine. On the other hand, they often are ill. An immunodeficiency associated with the disorder may lead to a lifetime of respiratory infections. The older a man with this disorder gets, the less his body may respond to medication, and the worse he may feel. Despite the fact that HED is said not to limit life expectancy, I have learned that the pain a sufferer feels may make him wish to die.

As I tell you this, you are nothing but a phantom, a presence, a spirit. Though you have not yet taken up a place in my womb, one day you could. We might find ourselves thus: you, a fetus with a genetic defect; your father and I, parents with an impossible decision to make — whether to bring you into the world. Right now we don't know if you will ever be conceived and, should you be, at what stage we might choose to end your possible life. Already you have taught us some of the most important lessons we will ever learn. If you were born,

you would teach us still more. But should we have a child to improve our character? To steady our moral compass?

Baby boys with HED look like little old men, with chubby jowls and gummy grins. "My little dandelion boy," my mother cooed to my infant brother, brushing her fingertips over his wisps of white-blond hair. When I was ten years old and people were startled by my brother's looks, I'd tell them, "I would love to have a baby like him someday." My mother explained to me that I possibly could. Since then tests have confirmed it: Half of my eggs carry the gene mutation. One in four of my pregnancies will produce a healthy girl. One in four will produce a healthy boy. One in four will produce a healthy girl who is a carrier, like me. And one in four will produce a boy with HED.

My baby brother was wonderful indeed. Still is. Smart, funny, tall, smooth skinned, and strong, he does wild impressions at holiday meals, swoops the cat up from his great height and snuggles her, not caring if everyone in the world sees him. My brother is loving, creative, complex, and pained.

I have heard other women whose siblings have HED say, as I once did, "I would be proud to have a son like my brother." But now I want to ask them, *Is this really about you? Is this really about how much you would love the boy? Have you tried to imagine the pain he might suffer?* Sometimes people don't believe me when I insist that I am not afraid to raise a boy with HED. "This is not about my life," I tell them. "It's about his." But when I am honest with myself, I find that there is no clear line between the two. My child's good fortune will nourish me. My child's pain will break my heart.

How can I imagine your life, its possible suffering and its possible joy, and then make a decision about whether that life is worth living? How can I even guess?

I once stood at my grandfather Earl's grave. He died when I was a baby and is buried beside his mother in Kimball, Nebraska, where sprinklers leap over the cemetery's green grass in summer. Beyond the lawn are the rocky, dry wheat fields where he grew up. He was lucky to have survived his childhood. At forty-nine he died poor and alone, his organs exhausted by infection and decades of drug abuse — chemicals he'd wielded against his pain, like a fly swatter waved at a dragon. He was in the midst of mapping out a plan to save the world. He still believed his lost wife would return to him, his estranged children would be awed by his inventions, and the medical community would greet him with prizes and fame.

Because I never knew your great-grandfather, his life is just a story to me. But I trust his stark tale and the warning it gives. I allow him to represent my worst fears. I tell myself that he would be happy to know that I do this.

What makes a life go wrong? Not just our genes, certainly, but also the ways people react to our genes. It is not a big nose or crooked teeth or an acne-prone forehead that makes a child shy and full of self-loathing and determined to prove himself. People give those genetic traits meaning by judging them good or bad, beautiful or ugly, strong or weak. I know my future children will be judged regardless of their health. Still, I feel compelled to shield them from any harm I can.

I would consider preventing your birth in part because of the reactions others will have when they see you. In the future that I fear, these reactions will become a kind of reality for you. If someone tells you that you are sick, you will feel sick. If they tell you that you are weak, you will feel weak. If they tell you that you are ugly, you will search desperately for ways to look handsome.

I will tell you that I love you, and you will know that I mean it. I will never tell you that I feel guilty, but you will know that, too, by the way I dote and worry too much about what you eat and how much sleep you get and what the children say to you at the bus stop. (Have they called you "cancer boy"? Have they said that you look dead?) I will come early to pick you up from school and stand in the gym doorway and watch the other boys: Do they pass the ball to you? And I will listen to the tone of the girls' voices as they chatter around the drinking fountain where you go to wet your t-shirt and cool off. In summer I will supply you with spray bottles and fans. In winter I will buy you balms for your dry lips and make you button your coat. You will feel crushed by my protection.

One day I will tell you, as if I happened to think of it just then, that you could use my makeup on the shadows beneath your eyes if you want. That you could use my pencils to draw in eyebrows if you feel like it. I will get angry when you don't put Bag Balm and Eucerin, those thick healing creams, on the patches of eczema on your skin. I will be angry if you scratch until you bleed at night. I might yell when you don't use saline in your nose, even though it makes you sneeze and cough. I will believe that you are making the others not like you. You will tell me that other children, children without HED, have sinus and skin problems too. You will say that children don't often judge you. You will try to convince me of this, but I will not hear it, because I will be too immersed in my project of undoing damage.

This is how a life goes wrong.

I never understood my great-grandmother Josephine's guilt about Earl, her eighth child, her baby boy, the one she kept pulling sadly under her wing. What choice did she have? She couldn't have known that Earl would be born with a birth

defect. There she was with her husband on the dry farm, their boys growing up and leaving. Only daughters remained. Getting older, Josephine and her husband needed sons, and this too-hot boy was all she could manage in the end. No one blamed her — except, perhaps, her husband, whose back was breaking. But little Earl must have known, before he knew many things, that his mother felt guilty about something.

Earl grew up to be a chemist and a medical professional, and he knew, by the time it mattered, that he had a genetic disorder that his children could inherit. Still, he didn't know that he could pass the mutation only to his daughters, who would almost certainly be carriers with no symptoms. Earl must have felt so lucky when his baby-doll girl arrived, followed by his two sweaty, yelping boys. He must have felt anointed. But his pain and addiction pulled his focus from his children. And his wife was too practical for tenderness. Along with the mutant gene, my mother inherited something else from her father: a sense of injustice about her unhappy childhood.

By the time my mother married, she knew there was a risk that any boys she gave birth to would have HED. She might have adopted, but the thought never crossed her mind. Having babies would be my mother's deliverance. To recover from her suffocating childhood, she would make a family of her own. She would flood her offspring with attention, as if to prove it could be done.

My mother's guilt over Luke, like Josephine's over Earl, has always seemed unwarranted to me. Both women needed children in order to survive. Neither had a choice: no test had been devised. It wasn't until years after Luke's birth that scientists discovered the location on the human genome of the HED mutation. Thrilled, my mother called me in my college dorm room to tell me there was now a test for the disorder: Women could know whether they had gotten the gene from their mothers. Mothers-to-be could discover whether their male fetuses, and even embryos, carried the defect for HED.

What would my mother have done if she'd had such a choice? During her courtship with my father, she'd followed him into Catholicism, and its clear-cut rules suited her. She might have listened to Church doctrine and said no to abortion. Or, confronted with the possibility of giving birth to a boy who would be like her father, she might have gone straight to a clinic. She wonders now. It is a question she cannot answer. She is, of course, happy that Luke is in the world. That is another thing entirely. The question is not about what is. It is about what might have been.

Women hear all the time that they must break their family's destructive cycles. I look back at the cycle of guilt in the carrier-mothers before me and wonder: *Could I be different?*

"I wouldn't want to pass this on," my grandfather Earl told

the best man at his wedding. He was hesitant to make babies with his new wife, not aware that a daughter — my mother — was already growing in his bride's womb. "It gives you pause," he said, stepping toward the altar.

Fifty years later I hesitated to ask my brother to participate in a blood test, to let scientists examine his genes alongside mine. "I don't want you to think there's something wrong with you," I told him.

He shook his head and held up his hand. "I wouldn't want your kids to have it."

Because of the test, I am the first woman in my family to have this choice. If I have you, a son with this disorder, it could mean only that I wished it. And I do not.

(end of excerpt)