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The Cards I Was Dealt

My Life With Familial Hypercholesterolemia

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I don't remember a time in my life without the word cholesterol. The images, explanations, and feelings over this word have changed through the years, but it's always been there. I have familial hypercholesterolemia (FH). My low-density lipoprotein (or "bad" cholesterol) levels have never been "desirable," and I have xanthomas—yellowish cholesterol deposits under my skin–around my eyes, behind my knees, and under my arms. My grandfather had a fatal heart attack at 30 and my mother had open-heart surgery at 42. These are the facts, but just writing those simple statements brings tears to my eyes and puts fear in my gut. This story isn't about the facts, though. This story goes beyond low-density lipoprotein, PCSK9 inhibitors, and statins. This is my story as a person dealing with the cards I was dealt.

My first blood test was when I was ≈9 years old. It wasn't good. While the exact breakdown escapes my memory, I am certain the total cholesterol level was ≈420. My mother cried, which made me cry. I had no idea why this was sad, but when you're a kid and your mommy is crying, you cry with her. I don't remember the doctor being sympathetic, because they usually weren't.

Growing up in Florida, my parents never had health insurance. Luckily, the state offered a health plan for children of low-income homes called Healthy Kids. While it meant I could go to the doctor, the parameters of the program meant I could simply visit the hospital and whatever doctor was in their pediatric residency at the time. With each new doctor and new set of laboratories, we met disapproving shakes of the head and lectures on my diet. My parents tried to take care of it with the knowledge they had. My mother lost her father as a child, and she had low expectations for her own life span, so they knew this was serious. We followed diets but without medicine approved for a child, there wasn't much more to do. No one had any new answers, and the doctors offered little help.

My memories of doctor visits as a child are not sprinkled with lollipops and stickers. I hated it. I hated all of them. With every visit my mom had to re-explain that her dad and his brothers died from this, and that we were trying our hardest. They nodded along but I often felt like they weren't listening—like they didn't care because they were busy and important. Then they turned to me. During their repeated lectures and food pyramid explanations, my mind would wander to horrible places. I stifled cries while thinking things like, "this is so unfair," "maybe I should never have children because I don't want them to deal with this," and "I don't want to die." Doctors watched me become visibly upset and never offered a kind word. Never. Even a simple "it's not your fault," would have gone a long way. Puberty is hard enough on a girl without the added effects of hearing the words "cholesterol" and "fats" at every turn. Needless to say, I still struggle with body image issues.

When it was time to go to college, I was too old to be on Healthy Kids. Without health insurance, there was no way I could afford my statins on a student's budget. At that point, though, I was so jaded by doctors and the healthcare system, I had decided to ignore the problem anyway. Nothing I had done had ever been good enough, and I was convinced it never would be. I developed my xanthomas and covered them with tanning and makeup. Every now and then I got my blood checked at the school medical center and filed the results away with little thought. I just pretended everything was normal and told few people about my cholesterol.

Then I got my first job. I had accepted a position working on a cruise ship. I was over the moon, and then I was told I needed a medical examination to be sure I was fit for duty. That meant doctors. I had avoided them for the past 4 years, and now a doctor was all that stood between me and my dream job. I took all the money I received from graduation and paid out of pocket for the tests and examinations. I sat in yet another examination room waiting for yet another doctor. I was full of nerves and anxiety at the thought of more lectures. What if my cholesterol meant I wasn't healthy enough to go out to sea? I was prepared to defend myself against the enemy—the doctor.

He walked in, and I was surprised. He was young and had a rock and roll t-shirt on under his white coat. It was different, but I wasn't about to be subdued into a false sense of security. He may have looked cool, but he was still armed with my laboratories and a medical degree. He introduced himself, asked me about my new job, and took a look at my chart. He calmly looked at me and said, "so you have what is called 'familial hypercholesterolemia.'" I asked him to repeat it and then he explained in simple terms that it's a condition where my liver doesn't work like everyone else's and that's why I've had cholesterol problems for so long. It had a name. By George, it

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finally had a name. It was a real condition with a real name that people acknowledged! For years, I was led to believe that it was just high cholesterol because that's how it is. It was genetic luck-of-the-draw that needed no explanation—like having red hair or dimples. With 2 long words, this doctor gave me the validation I had needed my whole life. He reminded me of diet and exercise out of necessity and concluded that I needed medicine that was going to "kick-ass." At 22 years of age, I finally had a doctor who let me know it wasn't all my fault. That is all I ever wanted. I wanted a little more compassion. I needed a little more "care" in patient care, instead of judgments over an assumed unhealthy lifestyle. This doctor finally gave me the healthcare I had needed all along.

There was no ignoring the problem now. I had overcome the fear of doctor's visits, but little did I know the fear would carry over to the pharmacy visits. My new job, while amazing, did not offer healthcare to the contracted employees. Cholesterol-lowering drugs are not cheap. Not even close to cheap. Not cheap-adjacent, not even in the same city as cheap. Especially not when your doctor says you need the "kick-ass" name brands. Although the pharmacists in my life have been more understanding and sympathetic than the physicians, it's still embarrassing to cry at the doctor's office and then again at the pharmacy. There were lots of patient care programs for senior citizens or people on Medicaid, but I was not eligible for any of them. My answer? Credit cards. I bought my medication with a credit card and prayed I could pay it off somehow. It only heightened my resentment for my own condition. To keep from having a heart attack at 30, I had to go into credit card debt, while people with the magical health insurance could have those same pills for next to nothing. It never felt fair.

It has been my experience that the healthcare world can be scary, lonely, cold, and confusing. I have found allies in a handful of doctors, one lipidologist, and The FH Foundation, but it's taken a long time to find them. I'm 28 years of age and for the first time in my life, I feel confident in the way my healthcare is going. While part of it has to do with seeking out new doctors, much of it is to do with becoming my own health advocate. I read articles. I track and save my blood results, and I ask so many questions. Doctors are great resources, but they don't know everything. Eighty percent of cardiologists aren't even aware of the prevalence of FH, and 90% of people with FH are undiagnosed. People spend hours researching their cars, their real estate, even which television is the best for their den, but then take whatever one doctor tells them at face value. This journey into FH education has taught me so much, but the greatest thing I've discovered is an awareness and appreciation for this body I live in. It is the most important thing I own, and I certainly know more about how it works than my Toyota.

FH is forever. It's a lifelong condition that I think about everyday. It doesn't hurt, but it makes itself known in the xanthomas on my eyes, or in the pill caddy I restock every Sunday, but those are the cards I was dealt. I have days where I can still hear those doctors from my childhood, and I blame myself for my bad laboratory results. I still hate explaining it to new friends for fear of being judged. I still get angry about the ridiculous price of cholesterol medication, but I'm still here, and for that, I am so grateful.

Disclosures

None.

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