

In Hiding

Emily O'Brian, College of Arts and Science

I never dreamed that I would lose my hair. I thought it would continue to grow and pull itself into tight ponytails and flowing blonde curls. But one day, I woke up to find that the quarter-sized bald spot I'd had since the third grade had grown to a fifty-cent piece, and then to a silver dollar, and then before I knew it, a whole coin jar spilled onto my head, and I couldn't figure out where spots started and ended.

I've always known there would be a chance that I would lose my hair. Alopecia is part of my autoimmune disease. But I just assumed I would be the lucky one with APS Type 1 who wouldn't develop it. I developed my first spot in third grade. My first thought was, 'What if I become *bald*?' God forbid *that* ever happens. I remember showing one of my friends my first bald spot during recess one day, hoping for some reaction that would make me feel validated and hopeful. Instead she pointed and laughed, saying, "Oh my gosh, what is that?" After that, I never showed anyone else.

In the middle of eighth grade, it really started to progress. One night, when my family and I were getting ready to go out to dinner, my mom was helping me comb my hair when she noticed something.

"I think your spot is getting a little bit bigger. Let me pull your hair back to cover it."

It was this moment that began what would be a year-long process of hair loss. I started 2012 with a mostly full head of hair, and I ended it with about as much hair as you would find on your hairbrush after using it.

As I began to lose my hair, I felt that my alopecia wasn't as bad as other people's. It didn't fall out all at once in the bottom of the shower. I hadn't been born without hair; I knew what it was like to have hair. Standing over my trashcan, I would clean off the growing birds' nests of blonde locks clinging to my hairbrush. It was all so gradual that I didn't think it was something to really take note of, until other people did.

The hardest part was having my older brother away at college. When he left, he had a little sister with a full head of hair, and when he came home, he didn't.

"Why does God let so many bad things happen to Emily?" he once asked. No one knew how to respond.

My mom tried to get me to talk about it, but I didn't think there was anything to say. It would grow back. This was only temporary.

The second half of eighth grade was the most self-conscious time of my life. I started it by pulling my hair back every day, and ended it with just wearing a beanie to cover the spots, and hoped that whatever hair was left would suffice.

“Why are you wearing a hat in school?” kids would ask me.

“Because I’m allowed to,” I would reply with a shaky voice.

Other students weren’t allowed to wear hats in school, so people thought it odd when I was. My mom had to email my teachers at the beginning of the semester to explain what was going on, so that they would allow me to wear a hat. They were all very kind, and some of them went out of their way to let me know they would always be there for me. Two of my worst fears that year were that someone might see one of my bald spots, and that a substitute teacher might ask me to take off my hat. Thankfully the latter never happened, but as for the first fear – secrets can’t always be kept, especially one this big.

In the mornings, I would pull my thin blonde hair back tight with a tortoise-shell clip, so it would stay in place through gym class. Racing from the locker-room to my regular locker, I walked as quickly as I could manage without it looking like I was running from something. One day, I got to my locker, and pulled my hat out of my backpack.

“Hey, you know you have a couple of bald spots, right?” the boy whose locker was next to mine asked, pointing to the top of his head to indicate the area he was referring to.

“Yeah, I know,” I replied. Pulling my hat on tight over my head, I grabbed my lunch box and hurried to the cafeteria.

Eighth grade was full of doctors’ appointments. My doctors were trying to figure out different ways to re-stimulate my hair. I was desperate for any treatment, so I agreed to anything they offered. Steroid injections stung my head once a week for a period of time, until it got to the point where they had to inject every part of my head. It was painful and too much stress for my body, and it wasn’t actually achieving its purpose. The doctors tried to come up with unique and “groundbreaking” treatments for me, but none of them ever worked. There is no cure for alopecia. You can’t just re-stimulate something once the body has attacked it.

On the day that my class went to a water park for the eighth-grade celebration, my mom, older brother, and I went to a Mexican restaurant for lunch instead. Water parks aren’t the best places for hats and thinning hair, unless I wanted the whole world to know my secret. Later, I graduated from eighth grade wearing a grey beanie and a black sparkly dress. And as the summer days came and went, so did more of my hair.

When it started to get to the point where I couldn’t pull my hair back to cover the spots, my mom suggested that we look into getting a wig. I didn’t want one. We drove to a shop one day after school anyways. She said it would be better to know my options in case I lost more hair. She

wanted me to be happy and feel comfortable in my own skin. I didn't think that would ever be possible again. We were silent for the whole 45-minute car ride. When we arrived, I picked my heavy head off of the hard glass of the passenger seat window.

The store walls were lined with stark mannequin heads wearing wigs that reminded me of grandmas I had seen on TV. The smell of musk and discomfort filled my nostrils as I took a seat in the black-cushioned chair. My mom did all of the talking.

"She wants something that matches her normal hair color and that looks as natural as possible," she told the saleswoman.

The woman brought out a hairpiece that matched my hair color, but when the lady helped me put it on, the thickness of it weighed down my head. Fighting back tears, I immediately shook my head, and she took it off. I don't think they got a lot of customers with alopecia, let alone 13-year-old girls.

During the ride home, I broke down in tears. My mom started to cry too.

"Why does this have to happen to me?" I cried, and she responded, "I don't know, honey, but I am so, so sorry." That was the first time I cried about my hair loss.

My mom did a lot of research on alopecia and support groups. She found out that the winner of the Miss Delaware in 2010, Kayla Martell, also had it and was an advocate for girls like me. My mom sent her a message one day and asked her where she gets her wigs. Kayla recommended a place in Delaware run by a man named Mario. My mom made an appointment, and we drove the two hours from Maryland to Delaware. I had no expectations, except that I knew I'd be starting my freshman year of high school with a wig on my head.

This salon was much better than the last. We walked in and were immediately overwhelmed by the smell of floral hair products. Women and men were getting their hair cut, colored, and washed. The cream-colored walls glowed under the effervescent lights. The staff were young, nice, and used to girls like me. Mario was one of the nicest men I had ever met. His black hair and matching mustache reminded me of the Mario video game character.

I felt like a princess in his private studio. The walls were lined with beautiful mannequin heads that reminded me of runway models and movie stars. I chose the one I liked best, and he prepared the hair for me. He crowned my head with a beautiful blonde wig. The Chinese hairs were silk against my shoulders, and the blonde of the strands reminded me of the hair I had just one year before. I felt at peace for the first time in six months, and a sliver of hope glimmered off the blonde locks on top of my head. Maybe wearing this wouldn't be that bad.

The first time I wore my wig, my little brother said "You know that's not your real hair, right?"

My dad scolded him before I replied, "Yeah, I know."

The summer before my freshman year of high school, my parents and I attended to two conferences for children with alopecia. At both, I wanted to hide. They might have asked me to share stories of encouragement about owning my alopecia, and I just didn't have any yet.

At the first conference, I met a girl with whom I really clicked. She'd had alopecia since she was very little, so she was much more comfortable with it than I was. My parents and hers walked around town on the last day on the last day of the conference. Her confidence as she walked down the streets of the city bareheaded planted a seed in me. I wanted to be able to do that.

The second conference was at a campsite in Michigan, and my brother and sister came along. We played games by the lake, and the brother and sister helped me talk to the other girls with alopecia. Inspiring women spoke about different instances of them overcoming their insecurities. I left this camp with a sliver of comfort, knowing there were people in the world with this disease who lived happy lives and felt comfortable in their own skin.

In the fall, I walked into high school with the people I'd hidden from for the past six months.

"Wow, Emily, you look great! Did you get extensions?" numerous peers asked.

"Yep!" They didn't need to know the details.

I was very nervous on the first day of high school. I felt small, but so visible as I walked through the halls that day. What if people noticed? I did not want to be known as "the girl who wears a wig." My sister was a senior that year, and all of her friends knew about me, including her varsity-football-player friends, who said they would beat up anyone who dared to say anything cruel. Their support made walking into school that day a little bit easier.

Even though this process was difficult, I didn't want to show weakness; as a result, I didn't talk to a lot of people about how I felt, even my mom. Ever since I was little, I've been praised for being "strong" and "courageous." Showing weakness didn't feel like an option for me. As a result, I never told my friends that I wore a wig. Instead, my mom sent their moms an email so that they could then relay the message to their daughters. My friends were all very kind about it, and they supported me when I needed it.

Sleepovers were uncomfortable. I would sleep in my wig and wake with an itchy head covered in sweat. I'd call my mom to take me home so I could take it off as soon as possible.

I didn't know what to do when people came to my house. Home was a safe haven for me, a place where I could be my true self, with no judgement or questions from anyone. But when my siblings had friends over, the wig came out and my sacred place lost some of its comfort. I was amazed whenever I felt comfortable enough to show people outside of my family my true self. I knew my sister's boyfriend was a keeper because of how comfortable I felt with him from the beginning of their relationship. I never hid from him.

No one asked questions about my wig; they either didn't feel comfortable enough to ask, or they didn't know I was wearing one. No one, that is, except one person. My friend Charlotte leaned over to me one day in chorus and whispered, "So, why do you wear a wig?" I was mortified. How could she tell? Was this going to ruin our friendship? No. Instead, she became the person I could talk to about my fears and my hair. She was the only one outside of my family I felt comfortable enough to talk to. She became my best friend.

On Christmas Eve of freshman year, about one year since the moment my mom noticed the hair loss, I decided it would be a good idea to cut the straggly strands of hair remaining on my head as a 'Christmas gift' for my mom. She always talked about how she thought they looked so out of place, and how it would 'look so much better' if I simply had a smooth head rather than a head with random strands of hair coming out of it. But I enjoyed running my hand over my head and still feeling hair.

I asked my sister to help me. She was excited, so was I. Sort of. Waking up on Christmas morning, from the first sleep I had taken with a completely hairless head, I excitedly showed my mom what I had done. She was surprised and didn't know what to say. I anxiously handed her the small clump of hair that was her "gift."

"Honey, you didn't have to do that for me, you know that, right?"

Regret overwhelmed me. After the Christmas celebration, I ran up to my parents' room and burst into tears. Why did I do that? I had cut off the last piece of long hair I would probably ever have. The realization of this disease overcame me once again and became the worst Christmas gift I'd ever received.

My mom came up to see me with the movie I had gotten for Christmas, *Pitch Perfect*, and put it into the DVD player. I don't know exactly what she said, but I know she felt terrible and so sad for me. When I hurt, she hurt even worse. She lay with me as we started the movie, and I cried into her shoulder as she comforted me.

The summer after my sophomore year, I decided I was done with it all: the lies, the itchiness, the person I was pretending to be. I asked my best friend to take pictures of me without my wig on. They were the first pictures I had of myself without my wig on since the eighth grade. I crafted a caption in the notes app of my phone and slept on it to make sure it was perfect.

The next day, June 14, at around 2pm, my finger hovered over the 'post' button on Instagram. I took a deep breath, pressed the button, and watched as my picture posted to the feeds of my 500+ followers. I threw my phone across the room and put my head into my hands. When I picked up my phone again and saw that I had no notifications, my heart dropped. *I should never have done that. So stupid.*

But then I hit “refresh” and the first “like” for my photo popped up, then another, and another. My phone flooded with messages of encouragement and hope. I walked down the stairs that day and smiled genuinely for the first time in a long time, a smile full of hope, relief, and freedom. My mom wrapped me in a hug that made everything in the past two years melt to just memories, instead of reality. My new reality was this life, and I could tell it was going to be sweet.

After that, I started to go places with just my hat on. I saw friends who hadn’t known about my hair loss before my post, and I asked some of them if they had any idea that I was wearing a wig. A couple of them said they did, but others described my Instagram post as a “Hannah Montana moment.” They’d absolutely no idea.

The first day of junior year, I wore a hat instead of a wig, and you could tell I didn’t have hair underneath that hat. I got some stares, but with my shoulders pushed back and my head held high, I walked down the halls. My former teachers seemed puzzled when they saw me, and they didn’t know what to say. Nonetheless, their eyes glimmered with pride as they realized who I was becoming. To the peers who questioned me, I told them the truth: “I lost my hair.” So simple, yet the four most difficult words I’ve ever had to say.

My hair started to grow back during my junior year. I started to hope that maybe I would have a full head of hair again. Unfortunately, I was wrong, and the short blonde hairs that covered half of my head started to fall out again. With alopecia, hair falls out randomly. One day I may wake up with some growth in a spot I haven’t had growth in for two years, but then the next day the hair could fall out and I could be back to where I started.

I graduated from high school with just my graduation cap on my head. When I was beginning to lose my hair, I told one of my nurses that I wanted to graduate with nothing but my cap on my head. I didn’t let her down.

Coming into Vanderbilt, I wasn’t sure what to expect, but I was excited. A blank slate and a new beginning. Freshman year, I clung to my hats for comfort. But, as the semesters have passed, I’ve grown comfortable. Now I only wear hats when it’s really sunny outside or really cold.

I feel very neutral about my alopecia now. Lots of people ask if I have cancer, and while this assumption used to upset me, I now see it as an opportunity to educate people.

Probably my favorite thing about my alopecia is that I am conspicuous. Walking around campus, it is easy for my friends to spot me. People remember me easily. I’ve made friends with professors, campus dining workers, and custodians.

A lot of my friends at Vanderbilt have begun to ask me about my hair loss as we’ve gotten closer.

“Do you mind when people ask you about your hair loss?” one of my friends asked.

“No, I actually really enjoy it when someone asks me about it.”

To me, when someone asks about this aspect of my life, it allows me to open up about some of my most difficult times and allows vulnerability to root itself in our friendship.

I constantly wonder when or if my hair will grow back. Whenever I get a new patch, I don't get too hopeful about it. I don't think I mind being bald anymore. I don't have to spend money on hair products or services, and it takes a lot less time to get ready in the morning. But it's still difficult to think about the future. I do want to have hair on my wedding day, and I would love it to be my own.

I grapple a lot with the question of what I would do if a cure for alopecia were discovered. I can't imagine my life without alopecia now, but I definitely would never wish it on someone else. Should you cure something that has had a tremendous impact on your life? Would it make me just conform to the societal ideal of "all women should have hair" that I have been trying to defy for the past five years? I am not sure, and I don't know if I ever will be.