



*Sophomore learns to cope with health illnesses by focusing on and controlling certain aspects of her body*

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Sophomore Hannah Hobert’s Wi-Fi stopped working in February of her freshman year when East switched from Blue Coat to Cisco. The night that Cisco broke down she got 20 minutes of sleep. She broke out into a 105-degree fever. Hannah couldn’t go to school for a week.

She closed her eyes and laid flat on her bed with her palms face up and fingers spread apart.

“I am cold. I am cold. I am cold. Sahara Desert but at night. I am cold.”

105. 104. 103. 102. It was these chilling thoughts that Hannah recited to lower her temperature. After two years of wincing when she brushed past people which shot a needle-like sensation up her arms, sleeping through entire days, vomiting after eating anything except Pringles and hardly having the energy to stand up, she could do something to mitigate the pain. Hannah, 5’6 and 110 lbs, was bedridden and confused by what was happening to her.

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Hannah’s life first took a nauseous turn her second week of seventh grade when she missed the bus home from Indian Hills Middle School. Her stress that she had to find a new way to get home turned into panic and then severe abdominal pain.

This bus mishap is what Hannah believes was the official trigger of, what after months of tests doctors decided was, eosinophilic gastroenteritis. Eosinophilic gastroenteritis is a “giant cut in [her] stomach and every time [she] eats it’s like pouring lemon juice in the cut,” as Hannah puts it. This rare disease causes severe stomach pain, vomiting, cramping and weight loss.

It took three months of MRI’s and blood tests for doctors to figure out that it was eosinophilic gastroenteritis. For those painful three months Hannah just hoped to never hear the “c-word”: cancer.

Her father, Ben Hobert, began his own research, printing off stacks and eventually binders full of articles detailing what food could possibly be causing his daughter to scream at the uncontrollable pain. They tried walks at 2:30 a.m. to anticipate the morning sickness. Hannah tracked the foods she ate and the times it upset her stomach most: gluten, dairy, anything with flavor. The only food that didn’t cause stabbing pains was Pringles. There was something about the light and bland salted chip that wouldn’t initiate pain.

After finally being able to put a name to the pain, the Hoberts believed there was hope in moving forward and healing. However, this disease of sorts still continued with days of vomiting, weeks of sleeping and months of missing school.

Her best friends were Pringle cans from

Costco and her border terrier named Chai. Everything she needed was inside the turquoise bedroom she couldn’t leave: getting out of bed was like lifting a boulder. She didn’t leave her bed for Christmas that seventh grade year. And some days Hannah had to take baths because she couldn’t stand up for showers.

“There would be a one minute period where everything would go away,” Hannah said. “It was like my body was teasing me saying ‘hey this is what you’re missing out on just to remind you.’”

Eventually this cycle tapered and the five medications she took every day started helping Hannah’s stomach. Towards the end of seventh grade, Hannah was back on her feet and she attended school more regularly. That is until the beginning of eighth grade brought waves of angst and a new health problem to fight.

Hannah said eosinophilic gastroenteritis triggered amplified pain syndrome, a condition that causes a person’s nerves to overreact and make small motions or contact with others

feel like a slap or scratch. Days that she made it to IHMS, she shuddered at the idea of having to make it through the crowded halls.

“I would grip the rail of the stairs like I was trying to get up a mountain because the pain was so bad,” Hannah said.

“It was so loud and I didn’t really know anyone and on top of that, everytime I brushed past someone it was like a bunch of needles were in my skin.”

Zipper from dresses felt like nails digging into her skin. A tap on the arm felt like a five-star slap. The pain was so strangely severe Hannah wondered if she was subconsciously making it all up.

“[Doctors] always emphasized that the pain is real,” Hannah said. “It isn’t all just in my head.”

The syndrome causes Hannah’s nerves to react to any unexpected motion or contact with a fight or flight response.

For two years Hannah had no motivation to move. She didn’t read her favorite dystopian novels anymore. She didn’t write anything for the fiction book she started in third grade – as Hannah put it, her brain only halfway functioned. It was hard to think or focus. Hannah ached to learn something, to understand something, because she still didn’t fully understand what was going on with her own body. Time was foreign to her, days blended together because of the monotony, and this made it very difficult for her to remember things.

“It wasn’t like I went to school and could remember that on Monday I learned about cells.

I didn’t have that,” Hannah said. “It was me and my bed and Chai, the sheets would change once a week but it was still bed, no indicators. [...] If I threw up and couldn’t eat for a day I wouldn’t even remember that. So, I tried to learn languages on Duolingo.”

Hannah managed to accomplish 52 percent fluency in German. Her brain was finally moving. She felt productive for that 10 minutes each day. Then she started traveling to Horizons Academy every Thursday for two hours of discussion for the Homebound program with a tutor to keep her up with school.

The worst part of missing school was not knowing anyone’s name or what her teachers were like. In a geometry group project she didn’t speak up or talk to anyone in fear of throwing up from the pain resulting from stress. Uncertainty made Hannah reluctant to participate.

“I was never at school so my group would see me and assume I wouldn’t do my part of the project,” Hannah said. “I would never correct anyone even if I knew the right answer for the problem because I didn’t have any justification as to why I could tell them they were wrong,” Hannah said. “I was never there and they went to school every day.”

Hannah later heard that many classmates assumed she was a transfer student. She hears stories about substitute teachers taking attendance in classes and everyone sighing, “not here” when Hannah’s name

was called. But there was discomfort in telling people why she wasn’t at school or talking to people at all – it brought a sickening pity.

“Whenever I told people that I was sick I felt like someone died because they would jump to saying ‘I’m so sorry’ and ‘you’re in my thoughts,’” Hannah said.

Days with amplified pain syndrome looked a lot like days with the stomach disease: bed, pain and no school. However this time, Hannah wasn’t supposed to stay in bed and take medication in order to mitigate the pain the way she did when she suffered from the stomach disease. With amplified pain syndrome, the goal was to create more pain in order to decrease it or make it tolerable.

Hannah was assigned a strict physical therapy schedule to force pain upon herself at home: 45-minute walks around the neighborhood that turned her legs firetruck red, brushing her arms with a strip of velcro and stretching on the yoga mat beside her bed. It was the worst thing ever Hannah said.

While she dreaded the monthly visits to her physical therapist for push-ups and velcro, she enjoyed her trips to Madonna, her Children’s Mercy biofeedback technician.

Hannah sat in the “comfy chair” each

visit while Madonna hooked Hannah’s arms and head to a bunch of mini wires and a belt around her waist to track her muscle movement. Hannah liked Madonna. Conversations were normal and Hannah blushed as she explained that Madonna swore Hannah was her best student in biofeedback.

Hannah would start at a normal temperature and then Madonna would do a series of actions like slamming a door shut to cause Hannah’s heart rate or temperature to rise. Madonna showed her, through charts on a screen, how Hannah’s body reacted in different scenarios. This was something Hannah could see and understand after a bit of training to read the squiggly lines. She learned to control her own temperature, heart rate, sweat levels and muscle movements without seeing these machines but rather recognizing her own body’s reactions and telling it to calm down like the chilling thoughts.

This use of biofeedback helps dissipate angst before her nerves transform her body into a battleground and choose fight or flight. Nerves that amplified pain which would become sickness again, much like what happened when Cisco broke down. But at least she finally had a form of control as Hannah said. She could understand what was happening to her body when she used biofeedback. She knew how to focus and tell herself to relax.

Hannah taught herself to anticipate other people’s actions, learning to dodge a stray elbow in the hall or accept that her mom would brush against her arm when showing her something on the computer. This combined with the biofeedback helped her subdue the pain.

When freshman year approached, Hannah’s mantra became “Don’t get sick.” She would repeat this in her head until she made it from forensics to journalism everyday.

“It was great to not go in every morning and have her say I don’t feel good,” Hannah’s mother, Ann Hobert said. “I mean I had that attendance line memorized from calling in every day.”

Hannah brings biofeedback and Pringles with her to school every day. However, she never eats the Pringles. Hannah passes the chips – her staple for two years – around the table to anyone who is hungry. Her way of passing a token of comfort.

Now she practices debate, plays the piano and designs for the yearbook. Hannah is able to speak in front of groups of people and be a personable friend according to multiple classmates, when before she couldn’t even talk to peers. Not only is she a friend and active student, Hannah is described as a “really good speaker and debater” by a debate classmate of Hannah, sophomore Olive Henry.

She still uses the Sahara Desert at night to cool her temperature and sweat levels and breathing exercises to slow her heart rate. This will carry throughout the rest of her life, but for now, each day Hannah is able to say, “I am okay. I am okay. I am okay.”