

Sketch

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Normal?

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Olivia Langenberg

Luke was in the hospital again. This time he was having open-heart surgery. At the family meeting we had with the doctor the week before, Dr. Huckmuth told us he was going to "fix" Luke's heart and that Luke would feel "so much better" after the surgery. The thing is, it had never occurred to me that Luke did not feel good.

Luke seemed like an ordinary 5-year-old kid to me. Then again, at the time I was 12, it was the summer before middle school and I was focused on more important things like how to put on eye shadow. I had a vague understanding of the fact that Luke was not the same as Chloe, his twin. Chloe was taller (even though small for her age), could read, and was going to start kindergarten, whereas Luke was extra small (only 30 lbs at 5-years-old) and scheduled for pre-kindergarten.

On June 28, 2000, I walked into the Cardiac Intensive Care Unit the day after Luke's surgery. I didn't know what I expected to see, but what I did see was nothing I could have imagined. Luke had seven IV's plugged into various places on his body. To begin with, there was one in his neck, one in his left forearm and another in his right hand. A thin clear tube snaked down from under his Thomas the Tank Engine blanket and emptied his urine into what looked like a zip lock bag. His entire body took up less than half the length of the bed. His skin was as pale as skim milk and his lips looked washed of color. My parents had told me the surgery had gone well and there were no complications. Luke was going to be o.k. but I didn't really believe it. I watched the green blip of his heart rate on the monitor. The sharp angles of the EKG seemed somehow painful.

A nurse named Kathy came in and gently scooted me towards the wall. "Excuse me, Honey," she said. "I need to disconnect the EKG. He doesn't need it any more, cause he's doing so well. Isn't that great?"

Sure. That was great.

She carefully untied his hospital gown and peeled away what looked like little round vinyl Post-it's with wires attached to them. As she leaned over his bed, I

caught a glimpse of the incision in the middle of his chest. It was as long as a piece of string cheese and studded with staples. It looked like half a toy train track right there on his body. Luke loved trains. I wondered if he still would. I wondered if he would be different after they had cut open his heart.

The doctor had said he needed to remove a lesion that had grown at the base of his aorta, obstructing the flow of blood. He'd demonstrated by putting his thumb over the tip of a garden hose and asking, "What happens when you partially block the opening?"

I'd said, "It comes out faster?"

"Exactly," he answered. "And that's hard on the wall of the aorta."

My parents had known, shortly after Chloe and Luke were born prematurely, that he had a genetic heart defect that would eventually require surgery. However, because Luke was asymptomatic right up to the day of his surgery, they never really processed the magnitude of the defect with me. And when Luke had his first allergic reaction to soy when he was an infant, I thought it was not that big a deal, since I knew lots of kids who were lactose intolerant. O.k., maybe they hadn't vomited profusely for 48 hours and gone to the hospital three times like Luke had. Still, those seemed like isolated incidents to me.

But when Luke turned two and my parents noticed that he never turned his wrists over when he washed his hands, (I'd always thought it was just odd that he put the soap on the top of his hands rather than in his palms) they took him to the doctor who diagnosed him with bilateral synostosis – a birth defect where the forearm bones are fused below the elbow and prevent full wrist rotation. The doctor recommended Luke be seen by the Center for Disabilities and Development in Iowa City.

I added it up in my head. He had a bone abnormality. He had a heart defect. He had severe allergies and he needed thick glasses and didn't really talk much yet. That was when I realized Luke was destined to be different; not as in he-likes-ketchup-on-his-toast different, but different different. Irrevocably different.

Early in the morning of September 11, 2001, I was in school, watching news footage of the World Trade Center crumbling into a pile of death and destruction. Every so often, the school nurse would come in and pull a student out of class. I figured out that they were going home because this tragedy had touched them personally and someone in their family had no doubt just died. Although I realized

the severity of the situation as it unfolded, I remained somewhat detached and was glad I had no family members who would receive awful news that day.

When I got home from school, Luke was playing with his wooden train set. A locomotive had just derailed as he took a curve too fast. "Boom! Crash!" he shrieked. "Olivia look! My train crashed! It's o.k. All the peoples are safe!"

I learned over dinner that he'd gone to the gastroenterologist that morning and been diagnosed with Celiac's disease - a total intolerance to gluten - and that he would never again in his life be able to eat wheat, oats, barley or rye. Luke ate pale rice noodles and steamed vegetables and talked nonstop about the storm clouds looming outside and whether or not it would rain. The rest of us had take out pizza - stuffed crust - my favorite. A pan of brownies cooled on the counter. I wondered, had Luke ever had stuffed crust pizza? Had he missed his chance forever? I asked him how his doctor visit had gone.

"My doctor disappointment?" he answered. "Oh. Guess what? I saw three trains in Des Moines! It's my lucky day!"

That night, as my sister Sophia and I were negotiating a clothes swap for what we wanted to wear to school the next day, we discussed how awful it would be to be a kid and have to live on a restricted diet. "That would suck," Sophia said. "I think brownies are my favorite food. And what about cake?"

"Oh my gosh," I said. "No cake? I think I'd rather die."

For his entire 6 years, Luke's body had reacted to gluten as if it were toxic and, unbeknownst to us, in the process he'd lost all the villi in his intestines, which is why he was so small, skinny and short.

"Don't you think it's weird," I asked Sophia, "that Luke is so different than us? He has all the medical problems in the family. Even Chloe, his own twin, is normal. You know, regular. And has no problems."

"Yeah," Sophia said as she held up her offering of a denim mini skirt and a baby blue sweater. "Now which one do you want?"

In 2004, when I first got my driver's license I found myself taking Luke places I didn't want to go: the train station to sit and wait for random trains, Wendy's - the only place he could eat fast-food French fries, the Channel 8 open house for weather enthusiasts. I was 16 and annoyed by how he wanted to spend time with me. My friends had normal little brothers who played video and computer games, were in Little League baseball and only bothered them when there was absolutely nothing else to do. Because of his fine motor difficulties/elbow joint abnormal-

ity, Luke could not manipulate most video game controllers enough to become engaged with them. The one time my parents enrolled him in Parks and Recreation soccer, he spent most of his time out in the field, yelling at the wind about high pressure and low fronts. His teammates swooped past him and worked together to score a goal. Luke was constantly asking me to tie his shoes, make him an ice cream shake or watch the weather forecast with him. I wished he would just shut up. I found myself resenting him for being weird and I wanted him to be normal. Although I knew it was selfish, I couldn't help being irritated.

Then he began to develop odd tics. This irritated me too. Was the weirdness never going to end? He would clean his mouth with his tongue after every bite he chewed, sniff repeatedly when his nose was not running, make a weird stepping motion with one foot across the other and raise his hands in the air when he was excited about conveying something really important. Maybe he was just a hyper little kid who liked clean teeth? Who liked weather and trains?

It seemed to me his oddities were his own quirky preferences and so he could choose to stop the weird behaviors. This made it frustrating to be around him because he didn't stop. It became too easy to focus on what was wrong with him, rather than what was right. "Luke, stop that. Luke, shut up. Luke, quit bugging me," I said repeatedly.

My mom took Luke back to the Center for Disabilities and Development to the Child Psychiatry department. He was diagnosed with Tourette's syndrome - a neurological disorder wherein the patient exhibits certain repetitive vocal/motor sounds and movements. Another feature of Tourette's is obsessive thoughts and preoccupations. That explained Luke's relentless weather checking and his need for four weather radios in his room. The specialists in Iowa City said Luke had an overall genetic syndrome, but they weren't sure what it was because there was no other kid like Luke who had the same set of disabilities. Besides his heart defect and bone abnormality, he was likely to always have cognitive difficulties as well. They would keep him in their database in case something came up, but there was nothing they could do to change or "fix" him.

Understanding that what was wrong with Luke was biological/neurological and beyond his control, really changed my perspective of him. I reflected on my own genetic luck. All my vital organs worked. I could eat whatever I wanted. I could fully rotate my wrists. My brain did not tell me to sniff 20 times in a row or blink my eyes rapidly every hour. I couldn't imagine how academics that came so easily

to me would be difficult for my brother. For example, in high school I didn't study for a single test, didn't do any major projects and slid out with a good enough GPA and ACT scores to get me into the Freshman Honors Program at ISU. I didn't even remember learning cursive in 3rd grade and Luke's teachers said he was struggling with printing.

Some kids on the playground started calling Luke a "retard." I didn't want my brother to be a retard. I didn't want him to get picked on at school or have to take Special Ed classes. I still wanted him to be "normal." It was hard to let go of this hopeless wishing.

What I am coming to understand is that Luke is his own kind of normal. After all, the concept of normalcy is a social construct. When Luke goes for check ups to the Center for Disabilities and Development he's surrounded by other handicapped patients who constitute a wide spectrum of disabilities, and when Luke is in his 6th grade classroom, he's surrounded by other 6th graders, both more and less academically able than he is. Luke is the only child in his class who could identify every state by name on an unlabeled map of the U.S. Yet he's stumped by "What's four times four?"

Now when my brother calls me, genuinely worried, because he's seen on the news that thunderstorms are coming, I answer and listen. He knows my apartment is on the top floor and my building doesn't have a basement. "Olivia," he says. "I'm serious. There's a severe thunderstorm warning for Story and Polk counties. You need to seek immediate shelter."

"Thanks for calling, Luke!" I reply. "What channel should I watch to make sure I'm safe? What about hail? Is there going to be hail? Flash flooding?"

This gives him the opportunity to talk about what he loves and know that he's being taken seriously. A few years ago I might've said, "Luke. I don't care. You're so weird."

I've also come to realize that Luke has the most positive attitude of anyone I know. He is unconditionally in a good mood. He waves to people he doesn't know and introduces himself to every cashier he meets. "Hi. I'm Luke. What's your name? Did you hear there's a big cold front coming in from the west?" And then he claps his hands gleefully. I can never leave the house without getting a hug from him. For a kid with a heart defect, he certainly has a lot of love to offer.

Because of his good-natured spirit, however, Luke is vulnerable to bullies

and has trouble making friends. It's like he's unnaturally happy and his peers think that's weird. He's never really had any friends. He's never been invited to birthday parties or had a sleepover. When he was in fourth grade, a first grader punched him in the face because he "wouldn't stop" singing. Yet Luke rationalizes other children's meanness by saying things like, "Oh, well. Maybe he didn't get enough sleep and he's grouchy."

I've never not had friends. I've been to countless sleepovers and birthday parties. Other than the usual playground disagreements, I've never been the target of personally directed unkindness.

This year Luke has started middle school - a socially difficult time for any child. Yet, Luke seems to be unphased by his own social awkwardness. In fact, he's put himself in the position of being a role model to another child in his Special Ed classroom. His friend Thomas is in a wheelchair and can't move or communicate orally due to his cerebral palsy. Luke obviously understands that Thomas is severely handicapped; nonetheless, he doesn't view this as a problem. "Sometimes, it's kind of gross when the spit bunches up in Thomas' mouth," he says, "but it's not his fault and I don't make fun of him and he's a good listener." Luke quickly learned that Thomas can respond to yes or no questions with a thumbs up or thumbs down gesture. He sits with his friend at lunch every day and especially enjoys earning free time on the computer so he can read Thomas the weather forecasts.

I envy Luke's immunity to social conformity. I have grown up in a world where mentally and physically handicapped individuals are sometimes considered repulsive, or second-rate human beings. I've witnessed people shunning Luke. This fall, during a high school parade, when the drum line was doing a cadence, Luke stood on the curb, dancing in oblivion and totally enjoying himself. I noticed some students in the band pointing at him and laughing. Whereas before I might have been embarrassed, now it just makes me sad for Luke that people don't understand how much he enjoys life, despite his daily struggles.

I was raised in a very accepting family, taught to have compassion for differences in personality and lifestyle. Yet, socially constructed ideas of normalcy can penetrate even people with the best intentions. I have to remind myself to be patient with Luke. Some things that seem trivial to me are imperative to him. He didn't choose to be who he is. He can't unfuse his bones, or stop the neurological impulses from firing. And through it all, he's still a kid who will say, "I had a great day!" even if he was pushed off the jungle gym.

My little brother is a very positive person in my life, and even though he's the "disabled" child in my family, he always encourages me to be the best that I can be, whether he's telling me how smart he thinks I am or just drawing me a picture of the two of us at the beach.

Once my sister Chloe asked, me "Why is he like that?"

"What do you mean?" I asked.

"Happy all the time," she answered. "Is it because he has some kind of syndrome?"

"I don't know," I answered. I looked over at Luke.

He was at the computer desk, dancing and cheering, "Woo hoo!" at the cancellation of a flash flood warning. He scooted over to me and raised his hand to give me a high five. His joy was contagious.

"But if that's a syndrome," I smiled, "I want it, too."