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Funny Looking Kids

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FUNNY LOOKING KIDS

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Senior Honors Thesis May 2010
Carnegie Mellon University

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1. HAND

The first thing you notice about my sister is her head tilted to the side, connected to her S-shaped spine that causes her to stand bent with one hip out, and her left leg bent at the knee, obviously longer than her right by an inch or two. Just from her appearance you know that something is not right, that there is something not normal about her. Then you start noticing the little things: her yellow and ground down teeth spaced apart from twenty years of thumb sucking, food in her hair and down her shirt from trying to feed herself, and a callous on her hand covered in scabs and warts.

The callous is my least favorite part about Christina. I don't remember when it became a part of her, but I know it was none of my family's doing. The quarter sized bump that takes over half her tiny hand is from years of biting her own skin when she becomes frustrated. Over a dozen times a day her hand goes to her mouth and she bites down hair; her skin should rip apart but it only cracks from being toughened over the years.

My parents would have never taught Christina to bite herself. They have never hit us, never spanked us, never even raised their voices until I was thirteen and started yelling first. They believed in time outs and Christina has received her fair share of being sent to her room; they would have never instructed her to hurt herself.

Christina learned to bite at school. An aide once thought it would be a good idea to show her to bite her hand. Some kids do it out of compulsion, like when they bang their head back against a wall or on a desk. It's out of frustration, but its also part of their disability; they

just can't help the repetitive action. Christina's hand biting came out of instruction and though we have always tried to change it by covering her hand in a brace or trying to have her bite a soft bracelet on her wrist instead, she still reverts to the self mutilation.

The constant biting has weakened her skin and the salvia keeps it moist, drawing warts into the cracks; that's why I hate it so much. Though seeing her mouth clamped onto her hand as she has a temper tantrum is hard, it's those warts that upset me the most. We have them burned off every month, but they keep coming back. Honestly, I'm surprised they haven't started forming in her mouth or on her face yet. I'm surprised no one in my family has caught them yet.

My biggest worry about the warts is that I get one. Christina has this thing about touching faces to get attention. Instead of just pulling on me to get my attention or saying my name, she invades my personal bubble by touching her moist fingers softly on my face. She'll stand behind our couch and touch my cheek as she asks softly for "clue please, mommy's room." I'll respond to her saying 'it's already on' or 'you know how to put it on yourself,' but she'll keep standing there, trying to touch my face and I keep knocking her hand away.

Sometimes I end up even moving onto the other couch, the one she can't stand behind, but she'll wobble over and sit by me, reach out and press her fingers to my opposite cheek to get me to turn in her direction and look at her as she restates "Clue please."

I think maybe even if she doesn't understand my worry of her hands on my face causing warts and acme, she knows I hate her hands there. She knows that and she does it all the time just to bug me.

2. MEMORIES

The first chronological memories I have of Christina aren't my own. They are videotapes I watched when I was in high school, curious and bored one summer afternoon at my grandma's house.

The earliest tape is of my sister and I in the tub together. Her chubby cheeks are graced with a smile of discovery as she slaps at the water and makes clicking sounds with her tongue. She must be only one or two years old because her hair still short with little ringlets about her face. My dad would always recite "*There one was a little girl that had a little girl. When she was good, she was really, really good and when she was bad, she was horrid…"*

I'm a sucker for the video camera. I splash our yellow lab over the side of the tub and sing every single song I had learned at school that day; I reveal that I sat with Gregory, my crush, during lunch and he shared his bag of fruit snacks with me.

The whole time I try to grab attention for the camera, Christina plays with the water. She splashes and imitates the sounds of the water with her clicking. *Chick-Chalk-Chick-Chalk*. Her bright blue eyes are mesmerized with the way water runs over her fingers and slides about the tub like a laundry machine from all my dancing movements.

"Mommmy! Wash my hair! Please! Can you use the Ariel cup?" I plead and the videotape cuts. There is complete darkness for a few seconds due to the lack of my mom's

editing skills or maybe because this was the early nineties when lives were recorded straight onto VHS tapes. Nothing is digital, not yet.

The scene has moved to my sister's bedroom. The walls are covered in a yellow striped and flower wallpaper that my mom found matching fabric in order to make curtains and two bedspreads: one for the crib and one for a queen-size bed when Christina gets older.

After looking around the room, focusing on the baby Mickey Mouse cut outs on the wall for a few seconds, the camera pans downward to the speckled carpet where Christina lays atop a white towel. Christina gurgles now, but doesn't wiggle around like a normal baby does when it's naked and free. A red tongue pokes out from between her lips as if she is trying so hard to say something, to come out with a word like *ma-ma* or *ball*, but its just too hard; she can't talk no matter how hard my mom prompts her with cooing and baby-talk.

My mom continues her cooing, but Christina becomes still and quiet. It's too early in Christina's life; my mom doesn't know what a seizure looks like yet. The camera is still on and my mom's voice is still cheery, she even pokes Christina's belly trying to get her to respond.

Then she notices that Christina is not just quiet, but *too* quiet. That her blue eyes have lost their bounce and stare blankly upward at the camera. Her hands and arms are flexed tight. Her lips are starting to turn purple. It took my mom over half a minute to realize something is wrong. The camera is thrown down to the floor.

"Scott! Scott come quick!" my mom yells out as she leans over my sister and starts blowing on her lips. She reaches for the camera to turn it off. "Scott I think she's having a seizure!"

3. ANGEL

Christina was born with her disability. I have never known her to be another way, so it's always hard for me when someone asks if I would rather she was 'normal.' I don't have any other siblings. It's just been me and her the entire time and though I sometimes feel jealous of my friends for the experience they have being so close to their siblings, I still don't think I would change Christina if there was a sudden cure for her disability.

However, there is no cure, not for her. Christina has a rare genetic disability called Angelmans Syndrome with a touch of Cerebral Palsy. Since the first is so rare, I just tell anyone who asks that she has Cerebral Palsy and they pretend like they know what that means just because they've heard the words before.

Angelman's Syndrome affects the 15th chromosome and happened during the replication process of recessive genes. In short, half of her chromosome didn't develop correctly and because of this, her brain never fully developed. She will never become smarter than a 3 year old, no matter what her age. Physically, she was never supposed to walk though she broke that diagnosing at the age of 6. Yet when she walks, she looks like a puppet on strings, jauntily and rigid. She drools constantly. She has blonde hair and blue eyes, matching no one in our family.

Angelmans is a rare condition, but Christina doesn't always match the diagnostic so my mom likes to tell people that Christina has "Christina Syndrome," that she has her own little disability. When people ask me to explain her disability, I usually change the subject.

4. RETARD

Sometimes, when I was in college, I could go through a week without thinking of my family. Though most would believe that those weeks were the ones that are packed with essays to write and hundreds of pages to read, they were actually the weeks that lacked work. When I had nothing to do for school, I tended to sit in the sun for hours. I read books that weren't assigned for class, watched hours of television shows that I missed during my busy weeks, and played like I'm a child by running around and playing phone tag with my best friends. I lived a life I have never been able to live before.

I always attempted to live this life during grade school. I tried to separate my family business from my social school life. I had to constantly work at keeping them separate. I never invited my friends over to hang out after school; I would tell them I was an only child. I made sure to hide from the Special Ed. aides. I never joined Best Buddies.

I was embarrassed for having a disabled sister, as if I could control her mental and physical capabilities. At the age of ten I suddenly thought that my sister would never be normal and yet at the same time learning what normal and popular were. Riding the short bus to school was not cool, but every morning it came to my front door and took my sister to school. It would pass me as I rode my bike to school with some of my friends and the aides would wave through the back window at me; I always pretended like I didn't see them, too afraid that it would be interpreted that I was the one riding that little yellow bus.

After elementary school I moved up to a Jr. High school that was too far away for me to ride my bike. My parents both had no time to get my sister ready to school and drop me off in time that they bought me a school bus pass, I was made to ride my own yellow bus. Except, thankfully, it was long and full of kids that were normal just like me. There was nothing to be embarrassed about. Unless you sat in the first few rows; then you were a loser.

I always nodded as if I was upset that I couldn't help my sister eat lunch, but secretly I was relieved I didn't have to ride the short bus or hang out in the Special Ed. Class room during recess. I was always afraid if I was caught around the disabled children or seen riding the short bus it wouldn't be seen as helping my sister, but then I would be classified as disabled. I would lose all my friends and be made fun of just like the Special Ed. kids were at school.

Every morning I walked the block down the hill to the bus stop and would wait with the other kids. We would chat about what we did for homework projects and snack on pop tarts if we had been too late for real breakfast. No one was every completely absorbed in the conversation. They kept an ear out for the rumble of the bus in order to line up. You had to get on first to get a seat near the back; the closer you got to the back, the cooler you were and I was one of the cool kids.

Except, there was always the trick of the short bus. Before the regular bus came to our stop, the short bus would always pass. Inexperienced kids would get in line as they heard the rumbling engine and its high-pitched breaks as it rounded the corner until they noticed the length. As the bus passed we would look at the windows and the disabled kids on their way to school.

I knew them all by name: Dylan the autistic boy whose family had to put locks on the cabinets and fridge unless they wanted him to eat everything he could. Ben with Cerebral Palsy,

too underdeveloped to do anything more than point to photos of what he wanted and had to wear a helmet to keep his skull from being bruised when he banged his head against the back of his wheelchair in frustration. Lindsay who could say my name when she was leaving therapy and wave a floppy hand to me as she passed.

One morning Andy laughed as the bus passed.

"God, look at those retards!" he shouted so loudly even the aids on the bus turned to stare at him through the grimy bus windows.

He started slamming his head backwards in the air imitating Ben's frustration. Kids at the bus stop started laughing with him, imitating him, hitting a floppy hand against their chest and making noises like a cave man. I watched this all unfold as the bus passed and worked its way up the hill towards my house for its last stop; no one knew my sister was the next passenger.

I hit Andy over the back of the head with such anger that his hat flew to the ground; there were tears in his eyes when he looked up at me.

"What was that for?" Andy screamed at me.

"Don't say that!" I screamed back.

Retard.

I hated that word with such a passion that I began hitting anyone who used it. I would snap at them and tell them to never say it again. It felt so ugly rolling off my tongue that I couldn't even say it, but just referred to it as *that word.*

"Don't use *that word!"* I would scream at kids. "*That word* isn't funny!"

No one understood my dislike of the word because I was still too embarrassed to admit that my sister was disabled. I had refused to ever point my sister out at lunch or explain to my friends I didn't want them over because they would see that my sister was *that word.* She was

lame and stupid according to them and if she was lame and stupid, then I would be lame and stupid and I couldn't have that. I needed to have friends; I needed to be popular; I needed to have a life outside of home.

5. RACHEL

When I was four, my mom took me with her to physical therapy every day and instead of whining about sitting in a waiting room for an hour while the PT stretched out my sister, I read through every issue of *Highlights* in the waiting room and would celebrate when I figured out all the puzzles within it's pages. I learned the names of the PT's and secretaries; I even learned the names of the other patients. I was curious too, always asking them how they were that day, what they had for snack, and other things that were important to me at the age of four.

Yet one day, according to my mom, I didn't ask Rachel anything; I just stared at her with my lips set tight, my eyes glaring with furry, and my fists clenched tight. Rachel was physically disabled from birth with a cleft pallet that reached up to her nose along with some other undeveloped features to her face and her limbs were too weak to support her body so she was confirmed to the sort of heavy duty wheelchair that paraplegics need.

I had met Rachel before this day and had said hi, but never asked any questions of her. As I continued to see her, I stopped saying hi and my anger grew and my stare thickened in her direction as I waited for her to be taken back to the PT.

It wasn't until this certain day that my knuckles turned white and the crayon in my fist broke in two that my mom finally was done with my silence.

"Francesca honey, if you have something to say to Rachel, say it, but we don't stare," she told me and then encouraged me with a little pat to my butt to go up to Rachel. I didn't sigh dramatically or make a fuss. Instead I walked straight up to her, stood akimbo and asked:

"How come your bow always matches your dresses? It's not fair! I want my bow to match my dress!"

My mom and Rachel' mom burst out in laughter. I turned to my mom, annoyed at her laughing. "I want bows that match!" I repeated.

At the age of four, I didn't notice Rachel's physical appearance nor was I embarrassed to speak to her, I was just jealous of her clothing. The funny thing was, that was what Rachel's mom wanted. Later she explained to my mom that she dressed Rachel in such fine clothing, making sure she always matched her bows to her dresses to her socks so that people focused on how lovely Rachel was instead of her permanent disfigurements.

6. RECESS

When Christina and I were new to La Costa Heights Elementary School, I visited her classroom to introduce myself and volunteer a little help while they learned about Christina. Except the teacher didn't want that, not exactly. She asked if I could come in during my recess time to play with my sister and side with her at lunch to feed her so they wouldn't have to do it.

When I got home that afternoon I was devastated, thinking I had to give up all my friend time taking care of my sister. My eyes were red from crying in the bathroom for the rest of the afternoon and when my mom picked me up from school I wouldn't tell her what was wrong.

"Francesca Lee, you tell me what's wrong right now," she finally demanded of me as we waited for my sister's short bus to pull into the driveway.

"I'm sorry I'm a bad sister, " I cried to her.

Her harsh eyes suddenly fell and began to also tear up. "What do you mean a bad sister? You're a perfect big sister."

"Yeah but Christina's teacher said if I don't come help during recess and lunch I'll be a bad sister. I don't want to go help them every recess, I want to play with my friends. I already have to play with Christina when I get home," I told her, afraid she was about to break into me with a lecture about taking care of my sister and the sacrifices I needed to make because of her disability.

Except my mom said nothing. She was silent as the short yellow bus pulled into our driveway and as we watched the bus aides lower Christina in her hot pink wheelchair. She wheeled Christina into the house and asked me to give Christina a snack. I agreed, wiping my eyes with my dress sleeve and not sure if I was in trouble for being so selfish.

My mom walked into the other room and closed the door, yet I could still hear her muffled speaking first quiet and stern then loud and yelling. I imagined she was talking about me, about what a horrible sister I was, most likely asking my dad if I should be grounded or not allowed to go to the sixth grade dance.

She was in there almost two hours. Christina and I sat on the couch and watched cartoons. My dad appeared home from work early and instead of the angry eyes I was imagining, he ruffled my hair and gave Christina a kiss on the cheek before saying everything would work itself out. He disappeared into the room with my mom and more talking continued.

It wasn't until dinner my parents sat me down and explained even though Christina and I are at the same school, that doesn't mean I have to give up my life and my friends to take care of her. I wasn't being selfish- the teacher was. She didn't want to do her job and take care of Christina, she didn't want to learn and understand how to care for Christina; she just wanted the easy way out.

I felt horrible trying to understand if I was being a good sister or not. Was I being selfish wanting my own life? I was her sister, not her parent, not her teacher.

That was the last time I have ever felt selfish because it taught me that though I may love Christina, I couldn't put her in front of my life and my dreams. It's what helped me decide to go to college across the country, to experience freezing cold weather and discover I wanted to be a screenwriter.

7. HALLOWEEN

I was only two when my sister was born, not old enough to remember anything from that time. Yet I feel as if I have memories from those first years because of all the stories that I have heard my parents repeat again and again. And I wonder if any of the images that cross my mind are truly there or only what I have conjured up over the years.

I don't believe its possible to remember looking up at my mom after I just turned two as she was confined to her bed for months before she gave birth to my sister. There is no way I can remember the cold white frame of her bed twisting around in swirls that still reminded me of prison bars. My parents had that bed frame for years after my sister was born, that must be how I remember it.

And the memory of needing help putting on the slippers is a lie, for I was too young to be able to do such thing myself. It was Halloween. I was a leopard or a cheetah. Maybe I was a tiger. I know I have seen the pictures hidden somewhere in the photo albums that live high up on the self in the office, too large and falling apart to ever be looked at anymore. My mom loves those albums that remind her of a time before we really knew what we were dealing with.

My mom made my costume by hand, too anxious to do something as tedious as watching soap operas all day long. Doctors knew if she wasn't on bed rest by checking her feet; the skin on the bottom of your feet peels like a bad sunburn if you do not walk on them.

I can remember Cindy, the neighbor around the corner, Mormon, the same name as my mom, and her salmon color lipstick smeared on her white buck teeth asking me if I'm ready to go trick-or-treating with her family. I don't remember the names of her children, but they were teenage girls that let me borrow their costumes for future Halloweens.

I know that my mom was on bed rest the Halloween before my sister was born, my mom made my costume, and that Cindy took me trick-or-treating with her family. I don't know where my dad was in this situation, but he had to be there. He has always been there; he will never leave my mom and therefore I picture him curled up against her pregnant belly, whispering R.E.M. lyrics as if they were the bible. Later that night he'd lift me up on the bed and pour out my plastic pumpkin on the bed and go through the candy with me; my mom would pick through the candy to make sure it wasn't opened and laced with poison or razor blades.

My mom knew that something was wrong with my sister before she was born. I've overheard her telling women that she just knew something was different. The baby inside her wasn't active. My dad called me 'Fish' while I was in my mom's stomach after *The River Why*, a book I own but have never read. He had no nickname for my sister. She had been Christina before she was even born; she had always been an angel.

According to my mom she knew that something was wrong as soon as my sister was born. She slept too much; she was too quiet; she just didn't look right. They would call out to her and she wouldn't react in the same way as I did at that age. The doctors would tell her that she was just comparing this baby to me too much; that she was being anal and stubborn; that all babies are different as they grow.

Yet she heard the nurses whispering: "It's an F.L.K...."

Ever since I can remember my mom has been a stickler for details. Back then it had been making sure that the felt claws on my costume stood up straight and didn't weakly flap to the side like a store bought costume. Now she worries about cutting coupons and how the laundry is still on the coffee table in front of the TV when she gets home from a long day at work. She always wanted things perfect in the best ways and when no one would give her a straight answer about my sister, when no one would explain what an FLK really was, she raised all hell in the doctor's office, demanded her file, and asked to be transferred to another hospital.

I don't remember this part of the story ever happening. I could have been at my grandma's during this fiasco or maybe at the neighbors once again. My mom has never told me the details directly. I like to make excuses for her, that she was trying to save me or maybe she never wanted to live through the hurt once again. But she told pregnant women about to go through the same process or friends who don't understand her suffering this story. I would listen in as I ate my favorite PB&J: cut into four triangles, no crust, and Daddy *had* to do it.

When I was old enough to understand the story of her rushing to Kinko's to Xerox every paper in her medical file, I didn't want to hear it. I had heard it enough times secondhand to know it by heart. She ran into Kinko's and made copies of all her papers and read everything in that file. The doctors knew that something was wrong, but they had refused to tell her. I assume there was ranting about getting their licenses revoked and never working in this town again because I've heard this rant throughout my entire life repeated for more doctors, in-house care, teachers, school board officials, and any other authority-like figure that stepped into my sisters life and tried to control my parents thoughts about having a disabled child.

After Kinko's my parents went to my pediatrician, Dr. Ben, a short Jewish man with a thick black mustache and a daughter the same age. He was infamous for always having the best

toys in the waiting room, the best stickers when you were done, and a little koala bear clip on his stethoscope. He would be our pediatrician for the next twenty years.

"F.L.K.? They said that to you?" He asked my mom in shock.

"Not to me, but I heard the nurses say that."

"It's not really a medical term."

"Just tell me."

"It's something nurses say sometimes. F.L.K.; Funny Looking Kid."

8. PILLS

Some days, Christina has these freak-out meltdowns, or at least that's what I call them. She just breaks down into sobbing for no reason. She hits and kicks whoever is closer to her; bites her hand until it is raw and the skin is cracking; it doesn't bleed anymore. Her entire face scrunches up like a newborn baby; hot tears falling from her eyes as she screams bloody murder or squawks like a bird. It's the mix between a three year old having temper tantrum and a preteen having an angst ridden hussy fit. The only thing you can do is walk away until the crying stops and she recovers enough to be able to breathe.

Whenever she has these sorts of fits, there usually isn't a reason behind them. It'll be as something as little of asking if she wants pudding. She'll be standing at the television, fingers in her mouth, and I'll walk up to her slowly, smiling.

"You want some pudding?" I ask. The pudding has to be eaten mainly because I have to give Christina her medication. She takes five pills three times a day, all harsh drugs that would probably knock me out, possibly kill me via overdose, but they keep her seizures under control.

"No!" she screams and hits me.

"Christina you need pudding," I try again. She screams again and starts crying. I take a spoonful of pudding, put a pill on top, and shove it into her crying mouth. She eats it but she still continues crying.

"Yeah yeah, I'm such a horrible sister," I deadpan and shove another bite of homemade butterscotch and a pill into her mouth. "I'm making you eat pudding, how awful."

I learned sarcasm from both my parents, though both like to say the other taught me. My mom likes to remind me it's the lowest form of comedy, but at moments like this with tears being mixed into pudding cups, it seems appropriate.

"What a punishment!" I coo at her and she bites down on the metal spoon. The sound of her enamel clinking down and grating against the utensil is like nails on a chalkboard. Goosebumps litter my arm and I instinctively let go of the spoon, letting it just dangle in her mouth until she harshly wrenches it away and tosses it across the room; it leaves a dent in my mom's wood floor.

"God, why do you have to be such a brat?" I ask her, the sarcasm replaced with a combination of aggression and boredom: I'm aggravated this isn't going smoother- it's only five bites of pudding- and I'm bored because it's a daily routine that has been going on for the past twenty years.

I grab the spoon off the floor, load it with pudding and the rest of the pills. "Last bite," I warn her, shove the spoon in her mouth, and remove it before she can bite down. The action is so fast she barely registers she has food in her mouth before she swallows.

I wipe her mouth with the back of my hand to remove the pudding that has leaked down her chin. We look at each other for a moment laced with frustration. She grinds her teeth to intimidate me, but I only continue to stare. Neither of us want to be the first one to start a physical battle, to throw a smack or a pinch because we know that the person who starts it gets in trouble and the person defending themselves gets off free.

Finally our gaze breaks. She turns back to the TV and sticks her fingers in her mouth to suck on. I fix the volume so it's not blaring and return to the kitchen finish the rest of her pudding cup.

Her meltdowns don't always go like this. Sometimes they are never ending hours of crying that force us to put her in the room and lock the waist high baby gate we use to make sure she doesn't wake up and wander the house in the middle of the night. We don't know why they start or the point of them entirely, but they happen and we deal. Or at least we try to deal.

9. ABORTION

I was about fourteen when I learned what an abortion was. Of course I knew the word, understood it meant having a baby in you one second and out the next, but it wasn't until Health Class that I learned the procedure, what actually happened to a woman's insides, and what happened to the baby. And yet even after I learned, I knew I would get an abortion if I knew that I was about to have a child like Christina.

No pro-life speech has ever been able to change my mind because maybe it is killing a life, maybe it's making me a selfish murderer, but I know I won't be able to do it. I won't be able to go through all this again. Learning how to walk at age six, children shouting monster and running away, changing diapers four or five times a day every single day for the rest of my life. Even if Christina is in a home by that time, I don't think I could make myself go through it again. It's not fair to have to live through that struggle from the very beginning all over again.

And it's hard to say its not fair because then I sound selfish, then I hear those voices in my head that ask what about the foster families that take in dozens of children with disabilities, what about the sisters that go on to be physical therapists or doctors trying find a cure, what about the sisters that wanted to spread the love and did community service all through high school to help disabled people.

I didn't do those things. I didn't choose to have Christina as a sister; I didn't go be a PT or a doctor; I didn't even participate in Best Buddies. I feel bad and hate a little part of my self

for not doing those things, but I remind myself I do enough at home. At home even the simplest task of brushing Christina's hair turns into a wrestling match as I have to lock her between my legs so she doesn't wiggle to the floor and I have to keep my head back to make sure she doesn't head butt me and break my nose.

10. SEIZURES

Before the age of ten I knew how to spot a seizure like how I knew to look both ways before crossing the street or never get into the car with a stranger. It was second nature to run into Christina's bedroom after not hearing her for long periods of time to check that she was still tearing up pages of magazines or humming with her television. Usually when I rushed into her room she would be sitting there, making a mess as always, and have a smile on her face that was just glad to see me. But sometimes she would be curled up in the fetal position on her floor.

For the most part, Christina's seizures never were as bad as the ones that they show in the movies. There was a sudden stop of movement, a crumpling of her body as she fell to the floor, and her lips turning blue as she stopped breathing. My parents taught me to always rush to Christina first and start blowing on her lips before calling for help. I never knew what blowing on her lips did, but sometimes it would rouse her out of the stupor that she was trapped in. I would blow on her lips and call for help.

"Mom! Dad! She's Seizing! Christina is seizing!" I would yell between each blow. I would gather Christina into my arms and pull her close to my chest, still blowing if the color had yet to return to her lips. With the amount of seizure medicine that she took, four pills three times a day, Christina was sometimes able to fight the seizure off. She would pull herself out and blink at me several times before curling up into a tighter ball and falling fast asleep. I always could

tell the difference between the seizure and the aftermath with how she would suddenly cling to me for support as she slept; I would be afraid to move away from her until she was awake again.

Yet sometimes the seizures aren't always so easy. Sometimes they penetrated her body so hard that she wasn't able to fight against them. That's when my parents come running and take her limp body away from me and lay her on the ground. My mom checks her pulse as my dad blew on her lips more. I would stand to the side and watch.

"Francesca, get the oxygen," they would tell me and I would run to the hall closet across from my sisters room. I would grab the tank and wheel it over to them, connect the rubber hose and mask up, and crank the tank to have oxygen rush through the tubing with the correct pressure. I was only ten and I could work an oxygen tank with my eyes closed.

It was always hard to go to school after these days. Kids around me would be talking about how their older siblings taught them to catch a ball or how they taught their younger siblings how to sing the alphabet. I was just teaching my eight-year-old sister how to walk and she was teaching me how dial 911 and tell the operator everything she needed to know from location to what was happening.

There has only been one time that I've needed to call 911 and all I can remember is sitting on the front steps, praying to a God I wasn't even sure existed. I stopped going to Sunday School because I didn't like my teacher.

"Please save my sister. I'll do anything if you save her. Just keep her alive, please."

11. MORNINGS

There is nothing like waking up to the Mail Song.

It's just as annoying as your regular alarm clock, but instead of just snapping you out of whatever peaceful dream, it winds its way into your mind and becomes the soundtrack to whatever image. Unicorns and fairies dance to the Mail Song and Steve Burns pops out from behind a rock.

Sometimes the song is soft because Christina is in her room or the living room, and the song is just echoing through the house. Sometimes she clangs through my double doors and throws the purple radio at my sleeping head.

"Christina go away," I demand, but she'll just stand right there in front on me with the purple radio on the bed. She'll push the button for the Mail Song again and again. She won't leave until I groan with impatience, roll out of bed, and carry her out of the room. Then she squawks just like a bird, drawing my parents' attention to the fact I'm awake.

"Oh good, you're up," my mom will smirk as if she sent Christina in my room on purpose. "I'm going to Cost-Co, you can watch your sister or come along."

The choice after getting out of my warm bed against my will seems disgusting: more Mail Song or having to battle the rush of Saturday shoppers vying for free sample foods?

"I'll go with you to Cost-Co," I say and my sister, standing behind me, playing with that purple radio issues a loud 'HA!'

Though she's disabled, though she's only four feet tall, though I know I'm going to get yelled at by my mom, I reach out and smack her in the arm. It's not a hard smack, nothing that will bruise and Christina bruises easily. It's just the sort of smack a sister gives her annoying sister. My mom hisses at me to be nice and Christina looks at me, gray eyes processing just what happened, before suddenly smacking me with her plastic radio.

The radio clunks hard against my shoulder bone and I swear under my breath in pain. Christina laughs so I reach out and poke her stomach to tickle her, something she hates because she doesn't quite understand what it is to have someone force you into laughing.

"Francesca Lee, you stop that! She doesn't like it!" my mom calls to me and eventually I stop. Christina smacks me again, this time just with a slobbery hand. I smile; we still enjoy annoying and beating the crud out of each other.

12. PROMOTION

I'm never going to forget my 6th grade promotion. I was wearing a lightly blue princess dress, empire waist with puffy shoulder straps and little pink flowers sewn on with pearls in the middle. My hair was half up half down: a hairstyle I've always hated because of the way it pulls on my head when I take out the hair tie, but my mom has always loved since it kept my hair out of my face and still showed off my frizzy curls. I was wearing my very first heals, a soft silver pair that I practiced walking in for almost two weeks.

I was excited to be moving on from elementary school. By then I understood I was a little bit smarter than the rest of my class and was constantly getting in trouble for finishing my work while the teacher was still giving the instructions. I wanted seven different teachers with honors courses and some new friends. I didn't like the girls I was trying to be friends with; they were the mean and popular girls and I was acting cruel to others to fit in.

Junior High School would be my chance to make new friends as the elementary schools came together under one school, but first I had to get through my promotion. I don't remember the ceremony as we received our awards. I got a medal for having good grades and certificate for finishing the reading list.

What I really remember is looking out into the audience and seeing no one.

The blue picnic style tables were full of families, but my own wasn't anywhere to be seen. I hoped as I shook the hand of my principal that my parents were standing in the back of

the crowd, hidden by other parents. I said goodbye to my friends, received congratulations from other parents, and become lost in the crowd looking for my mom's pink leather jacket or my dad's scruffy mop of hair.

Instead my Uncle Joey, my mom's littlest brother despite already starting to lose his hair, weaved his way through the crowd and took my hand from behind. Together we walked to the garden by my little sister's classroom where my grandparents were waiting for me. They gave me hugs and I sat with them for a bit, but I had to ask my uncle:

"Where are my mom and dad?"

He frowned. "They're visiting your sister's class."

"Well then can we go there?" I asked.

My uncle shook his head. "Let's just wait outside for now."

When my parents finally came out of my sister's classroom, my dad was carrying my sister even though school wasn't over for another few hours. I had never seen him look so angry with his eyes set in a black dark stare and his jaw tight as if he was holding back everything he wanted to say. Christina was quietly sucked her thumb.

I didn't really understand what was going on back then, but I would hear the story for years to come. My parents weren't visiting my sister's class. They had peaked into the classroom to see how my sister was doing just in time to witness the teacher abuse my sister.

Christina was having one of her classic temper tantrums, biting her hand and kicking, and instead of walking away the teacher smacked her. As if this wasn't enough, she picked Christina up by the armpits, walked her across the room and threw her in a chair in the corner for a time out. My parents, grandparents, and uncle witnessed the whole thing.

This wasn't the first time my mom had problems with the school board, but it was the first time she truly witnessed my sister being abused. She had stormed in there and started yelling at the teacher for her actions. The teacher tried to blame Christina's anger: Christina kicked her and needed a timeout. The excuse didn't work. Hell, even at that age I knew that excuse would never work since I tried a million times to use it when I was caught harassing my little sister.

Later that afternoon, we celebrated my promotion at some fish restaurant I wanted to try. I had been so excited to try the new fancy restaurant, but after experiencing the abuse of my sister, all the happiness and celebration of the day was spoiled. My mom was still ranting to my uncle about what happened, my grandparents were paying more attention to my sister, and my dad was being his quiet, usual self, oblivious to what was going on around him.

While the day could have been a memorable celebration, I can't remember what I ate at that fancy restaurant or the gifts I received. I remember preparing for the day; I remember wanting to wear the dress again because I felt like no one got to see me in the princess gown I loved so much.

13. TELLING

The first time I told my friends about Christina was in the eighth grade. I remember it so clearly, even the red stretch-cotton shirt that matched the red stitching in my jeans that I was wearing; back then I needed to make sure every piece of clothing matched in color and size. I wasn't the popular girl; I had once been popular in the beginning of jr high school, but the mystique had worn off by then. I was only going to invite two girls over for a birthday sleepover.

But first I had to tell them about my sister.

In order to tell Kim and Lauren about my sister I brought them into the conference room of the teacher's lounge. I couldn't sit and had to keep pacing in order to keep my breath steady. My hands were shaking as if this was a test of their friendship and the final ultimatum if they wanted to be my friend. It was always if they wanted to be my friend, not if I wanted to be theirs. I felt as if telling them my sister was disabled gave them the right to dump me as a friend and move on to friends with normal families.

"I have to tell you guys something," I told them, taking a deep breath and drawing my words out. "My little sister is disabled."

For how worried I was, their reactions were a bit of a bit of a letdown. They both stared at me for a moment, nodded a bit, then said, "okay, is that it?"

Christina's disability didn't change the way they perceived me as a friend. After that I shrugged my shoulders and we went back out to lunch to go talk to the boys we pretended we didn't like and not to the ones we actually did like. The days continued and nothing changed; we were still friends.

14. GRANDMA

Christina and my grandma had the most beautiful relationship I could think of when it came to love. Even as her only sister, I feel okay admitting that my grandma loved my sister more. Unlike me, my grandma never thought of my sister as disabled or held back from her friends that she had a disabled granddaughter. I used to wonder if this is because she didn't know how to translate the medical terms into Italian, but it didn't matter. My grandma loved Christina with every bit of her heart and I know Christina loved her too.

Ever since Christina was a baby, my grandma has loved her. Since Christina couldn't chew her food, my grandma would make her fresh patina little enough for babies to swallow or grind meals up in food processors so my parents wouldn't have to give her store bought baby food. As an Italian grandma, food and feeding us were her other love, yet I like to think that she loved feeding Christina more than the rest of us. While we all just loved grandma's pasta, Christina needed it and became attached to it. When she got home from school she would ask for 'Nonna's food' and have an extra big smile on her face when I announced that we were having 'Nonna's pasta for dinner. There was just something about the food being from grandma that made Christina's blue eyes light up as if she were being given a cookie or ice cream.

As my grandma grew older and weaker, she stopped making the special pasta as often for family gatherings. Instead she would use prepackaged raviolis and the meatballs that come in the value-size pack at Costco. They were nowhere near as good and perfect as grandma's

regular food, but we all ate it with smiles and appreciation because we knew it wasn't the food that brought us together on Sunday afternoons. But as we sat in misery eating meatballs with way too much pepper, my grandma would hand feed Christina the special peas and pasta she made just for her. She made sure to always make Christina fresh pasta even if everyone else was getting the frozen kind. No one saw it as unfair, just more of grandma's love that no one should ever go without.

The lingering questions I have about my grandma's death are how Christina is handling the concept of never seeing grandma again. Though we attempted to tell her that grandma has gone to college like I do for months as at a time, I worry that eventually she is going to start asking anyways. Even with her mental retardation, she has to wonder where grandma has been and it hurts my heart to think that no one knows how to explain such a difficult concept to her. Christina doesn't understand 'gone forever' or 'never going to see her again.' She calls every single one of my friends 'Avalon' because I have a friend named Avalon, though she and Christina have not seen each other in years. I wonder if she is going to start calling every old lady she sees 'Nonna' or if she is going to know the difference that grandma is not coming back.

15. AMERICAN GIRL

My first semester in Chicago, I bought my sister an American Girl doll for Christmas. I got the tanned skin girl with curly brown hair; she looked just like me. For some reason I thought that when Christina was missing me, she would be able to play with the doll-.

Come Christmas morning, she didn't give a shit about it. When I gave her the doll, she just stared at me and then threw the doll onto the floor. It was an expensive gift and I feel pretty stupid for getting it when all it does is sit on her shelf, but I was trying to give her something to remind her of me while I was away at college.

Thankfully we've been able to explain my going off to college because of an episode of *Blue's Clues.* Steve goes to college when he leaves the show and though he makes appearances here and there, something about leaving with his backpack to go learn has made Christina be able to understand where I go for long periods of time. When I return she is always happy, gives me hugs, and latches on for a bit, but after a day or two it's like I was never gone. She doesn't seem to notice time or understand how long someone is away from her.

When I leave for school, she gives me kisses and we watch that episode of *Blue's Clues* just so she knows I'm going to come back and we can always talk on the phone. Not that she talks on the phone, but it helps me feel less guilty about leaving for so many months at a time when I know my family needs my help.

16. ANNA

When I decided to go to college, I knew that I wanted a school on the East coast to get away from my family. It's not that I wanted to escape completely, but I wanted to be far enough away that I didn't have to deal with my mom showing up on my doorstep every other weekend. I was also looking forward to watching the leaves change and getting to be in snow for the first time. I chose Loyola University of Chicago because of the scholarship they gave me that was solely based on my GPA. I didn't really enjoy the campus and it wasn't my first pick, but the money they were offering me was enough to make me lean towards the windy city.

Anna came from a strict family in both religion and culture. Her parents had both traveled from Poland to the states and as a first generation immigrant; she was also the first to go to college. But even with her need to go to church every Sunday, somehow Anna and I got along. We knew what it was like to have a culture and not faze into American society; being different didn't matter to either of us from the way we dressed in purple jeans and danced to hardcore metal music like it was jazz in the middle of a concert.

Together we went shopping at Urban Outfitters and found the strangest clothing that no one really could find fashionable, yet wore the pieces around Chicago with pride. Anna dressed more like a child. She was tall, a little over six feet tall, but with her dyed black bob and pink headband she reminded me of a four year old who was still learning how to dress herself. She wore skirts over jeans, anything with a pattern of hearts, and color was not only present, but

clashing all over her like a spilled paint set. In high school she was picked on too, she was made fun of for dressing weird, for being different. She knew what it was like to be different, and I thought that was enough for her to understand Christina and my relationship with Christina better than any friend I ever had.

Except when Anna met Christina, there was a moment where her nose scrunched up and her eyes widened before she could plaster on that fake smile, laugh, and tell me it was all alright. The little second before the fake acceptance showed me that even in difference, Anna and I were not the same. I can't decide if it was disgust or pity and don't want to define that moment with an adjective that is unfit, but there was something there, something she didn't like, some thought that passed through her mind that showed on her face. If she hadn't been staying the week, I probably would have awkwardly asked if she wanted to go get food or go out shopping and never bring her home again.

Yet Anna didn't seem to get it. When Christina touched Anna with sticky fingers, she flinched away and would remove Christina's hands from her body. Then Anna would go wash her hands and arms. In the afternoon as I waited for my mom to come home so we could take the car, Anna asked with her voice full of disdain and boredom, "do we really have to watch *Blue's Clues.* You could just not turn it on for her. Whatever."

I started at Anna in shock. Though I had turned off *Blue's Clues* multiple times before when I was on the phone or Christina needed to be punished for hitting, I never just turned it off because it was annoying. In fact, after so many years, Steve's voice had become white noise. It was buzzing in the background that I passively ignored until I was made to notice it by Christina turning up the volume on the television. Then I would only turn the volume back down, but never the turn the television off.

As the week went on, Anna seemed to grow crankier. Though she said it was because she missed her family, I could tell when she walked into the kitchen before she lapped on all the makeup she wore even to the grocery store because 'you never know where you might meet your husband' that she wasn't a fan of the Mail Time wake up call. My dad always tried to keep Christina quiet in the morning, but it's hard to cover up that song no matter how you try. We did our best to keep her happy, but Anna just couldn't settle in to living in my home or even being a visitor.

At the end of the week, I felt like I had lost my best friend. The reason I related to Anna was so well was because she refused to fit social norms. Yet just because she accepted my eclectic music taste, how I couldn't eat the red sauce in the cafeteria because it was nowhere close to my grandma's, and even how I wore Doc Martin army boots instead of snow boots that she would able to accept Christina. Anna had a little sister that was her best friend; I didn't think she could treat my relationship with my sister with such disdain. It was if she couldn't understand how I could love all Christina's faults and because of this, she couldn't accept me.

Once we were back in Chicago, Anna and I remained friends, but she never visited again. I knew by then she wasn't a real friend, just one for show. She didn't accept me because she related to me, but because she wouldn't be alone in the weird way she dressed. She wanted to be popular, would have been a cheerleader if she wasn't so lanky and awkward. She was desperate for someone to be weird like her, but she wasn't ready to accept how different I truly was.

In the end, Anna and I gave up being friends. We attempted living together for a semester, but we fought over her buying all the furniture since she lived in Chicago and I had nowhere to store the furniture during the summer. When I told her I was unhappy and was

planning to transfer schools, she stopped talking to me completely. She thought I was betraying her and leaving her alone, unable to see how depressed I was at Loyola and understand that the school didn't offer what I wanted for my future.

Anna wasn't a true friend; she wasn't going to stand by me for the rest of my life. She was using me to make her feel better about herself and not feel so alone. I supposed I was using her at first as well, alone in a distant city, not immediate family around, but when she met Christina everything changed. I can't be a friend with someone that doesn't accept my sister as well as me. Christina is going to be a part of my life until I die. Maybe one day she will be put into a home, but I want to live close enough to visit her. This is the problem I think about with boys I date. I had never thought about it with friends before Anna. I had always been so embarrassed to introduce my friends to Christina that I never had experienced the disappointment of having a friend not accept her.

The entire experience made me realize what a true friend was. It's a person that maybe you don't call every day, but they will be there for you and your family. They will support your relationship and not have a moment of disgust ass through their eyes before they cover it up with a fake smile and laugh. Real friends don't care; they interact with Christina and sing the Mail Song with her.

17. GENETIC

I was standing in front of the black bear exhibit at the Carnegie Museum. Through the glass I stared at the bear, trying to figure out if the fur is real, if taxidermy is really as creepy as they make it sound. My phone started to ring and I decided to pick it up.

"Hey mom, what's up?"

"Oh nothing,' her voice is soft and I wonder if she's keeping it down so the people at work don't hear or she has just finished crying after a memory of my grandmother came up.

"Awesome," I mumbled sarcastically and walked over to the next window: the Alaskan Black Bear, not to be confused with the Pennsylvanian Black Bear.

It was ripping open a salmon.

"Yeah but…so… I wanted to tell you not to get pregnant."

"Um excuse me?" I coughed on my words, choking at the very idea.

"Please don't get pregnant," she repeats.

"I wasn't planning on it any time soon," I said with a harsh tone a mother should use with a child. The thing is, we've had this discussion before. Like with my boyfriend before Gates, I got on the pill before we actually had sex since getting pregnant was not on my list of things to do before I graduate; it's barely on my list of things to do before I turn twenty-five. And my mom knows this because she pays my medical bills, so it's not like I could hide it from her anyways.

She took a deep breath, not thrilled with the sarcasm I learned from her.

"No, I mean. We went to the doctor yesterday; she doesn't think Christina has Angelmans Syndrome anymore," my mom finally explained.

"What do you mean doesn't think she has Angelman's," I trailed off as I walked over to the great big moose. My first boyfriend was nicknamed Moose because of his extremely big and fat nose. We didn't have sex. We didn't even kiss.

"Well Angelman kids, they usually can't say more than a few words. Your sister can string more than five together. 'In the car now please grandmas house,' its not a sentence, but its much more than any other child with Angelmans can do," my mom explained, picking up speed. "So the doctor wants to run tests again, make sure it's just a mistake in genetics like we thought it was instead of something hereditary."

I froze, eyes glued to the moose in front of me. I touched the glass, expecting it to feel cool like the snow in the display case, but it is warm from the heating system in the museum.

"So I could have a baby like Christina?" I refuse to have a baby like Christina. I reuse to let that happen to me again or to someone else who I love. I refuse.

"If it's actually something hereditary, yes. We probably need to bring you in for testing during Christmas break too," she said.

"Yeah, okay," I say. I step back from the display case quickly, needing a way to get out. "Hey I'm at the museum with some friends, so can I call you back later?"

"Okay, I'll talk to you later."

"Bye mom, love you," I say automatically before hanging up. I flip my phone open and closed twice to make sure that it hung up and my mom can't listen in to any conversation that might happen this side of the line.

I walked back to my house and when I go upstairs I turn my phone on silent so I don't have to talk to my mom again tonight. I got online and see that my friends are all on while doing homework. I told my boyfriend that I still needed to pack to avoid going over to his place for the night. I wanted to be with him, wanted to cuddle up to his chest and have him hug me tight in that tiny twin size bed with the blood red sheets, but I was still hiding from him. I couldn't tell him about the conversation with my mom.

18. COLLEGE

When deciding on what colleges to apply to, I had one requirement: not in California. Not only did I want to escape from home, but I also wanted to make sure I was far enough away to prevent all attempts of surprise visits from my mom. I didn't want to wake one Sunday, hung over and still wearing makeup from the night before, to her coming into my dorm room to lecture me about doing my laundry.

College was my way of escape. I could leave behind my family and become my own person. I felt as if living at home had held me back from being the sort of person I wanted to be. I never snuck out of the house even though there wasn't even a screen in my bedroom window or tried drugs. Of course there were a few times I fucked up, but they were more based on depression than rebellion. And ever since transferring high schools, I had been a pretty perfect kid; I wanted to get away and be the person I felt like I couldn't be with my mom yelling at me about my clothing choices or hanging back from a party because I had to baby sit Christina.

I only applied to a few colleges in California and though I got in, I refused to attend any of them. I understood my mom wanted me close, but I knew I needed to get away. I had to be able to make my own decisions without my parents or thinking about going home every weekend. I made a few exceptions to my need to get away, turning down a scholarship to swim at a small private school in Oregon because of its lack of transportation to the Portland airport

two hours away. I knew that if something did happen and I needed to be home right away, that I wanted an escape route available at any moment.

19. BOYFRIENDS

"How am I supposed to bring a boy over for dinner if you keep acting like this?" I asked Christina as she held tight to my sweatshirt with one hand and her other hand, fingers wet with spit, pressed to my face trying to make me listen to her.

"Eat!" She shouts in my face. I take a bite of pizza, spit it out, and then stuff it in her mouth. She chews and asks for more. I feel like a mother bird feeding her baby and somewhat disgusting if you consider our ages of twenty-one and nineteen. But I know if I don't do this, then Christina could choke since the Pizza was too rubbery for her to take a bite out of. That is, if she remembered to take a bite. Christina is more prone to just stuffing as much food in her mouth until she can't fit in anymore. I've had to give her the Heimlich three times in my life; three more times than any of my friends have given it to their siblings.

Boyfriends and Christina have always been an awkward topic. Like with friends, I had the hardest time telling boys that my sister is disabled. With boys it's more difficult because on top of asking them to be accept me and like me, I have to make them like my sister too.

Though I was too young to be thinking about it, whenever I dated a guy in high school, I thought about how he will deal with having a sister-in-law like Christina. There's more than if he can just be okay with her being a little different, with her hanging on him with her slobbery fingers and throwing neon orange VHS tapes at his head. My friends in general have to be okay

with things like that, but a boyfriend has to realize that this will be the rest of my life and eventually, one day, he might have to help.

It's been weird to think I'm getting to that age where I could possibly be finding a husband soon and I really do have to consider how he percepts both Christina and my relationship with Christina. I need a guy that won't mind having to live in the same state from her, possibly less that an hour drive away. My parents both agree that one day Christina will have to be put in a home, and though college proves easy to be far away from Christina for a few months at a time, when my parents are old or even pass away, I know I will feel the same *Rain Man* guilt for leaving her behind and continuing on with my life as if she never existed.

Brian was a chubby boy I met back in my senior year of high school at a benefit concert my school was holding for the homeless kids downtown. He was a friend of a friend that didn't go to the school and though not necessarily attractive, he had that that skater blonde hair and the right sort of dimples in his smile to catch my attention.

As cliché as it sounds, I've always looked at personality first when it comes to boys. I look for guys that aren't strict and commanding because how will they be able to deal with stubborn Christina that hits and pinches when she doesn't get what she wants. My dad and I tease that I am the only one allowed to hit her back, since I'm her big sister, but even then it's just a little swipe or tap to get her to stop pinching me or holding tight to my skin with her fingernails. A guy that wanted strict rules wouldn't be able to get along with Christina; he wouldn't be able to get along with me.

Brian was all sorts of playful. He told jokes the entire night, teased the bands playing with a toothy grin, and made me see how he was just a genuine nice guy with a bit of sarcasm

laced into his personality. It was pretty much my perfect kind of guy at the time since I wasn't even looking for a serious relationship; I was a senior in high school, already knew I was going to Chicago for college, and not looking to have something holding me down when I started my freshman year.

We only went on two or three dates before he met Christina. It was a pure accident; we were making out in my room when my mom came home with my sister from a doctor's appointment. I wasn't thinking of introducing him to my family any time soon and I was silently kicking myself for letting him convince me into bringing him home for a bit as I introduced my mom and sister.

"Um, mom, this is Brain," I said as we stood outside my door. I smooth down my hair since it was probably a dead give away of what we had been doing before she pulled into the driveway.

"It's very nice to meet you Mrs. Halleman," Brian said, giving my mom a handshake and a welcoming smile. My mom nodded and returned the greetings, but Christina's squawking as she entered the house, upset that she had to come home, covered them up.

"And, um, this is my sister. She's disabled," I explained.

"Oh what does she have?" Brian asked, his tone getting softer and some sort of empathy in his voice. I cringed.

"Angelman's, it's pretty rare. We just like to say she has Christina Syndrome," my mom answered for me. I stared at her; wishing she would shut up, say she was going to get dinner started, and that I should take Brain home. I didn't want him this deep into my life just yet. Hell, I wasn't sure I ever wanted him there.

"Oh, I think I've heard of that. I worked at a summer camp, we dealt with a lot of disabled kids there," he said and smiled down at me. I looked back with a blank face. If there is anything I hate more, it's when people assume that since they have encountered a disabled person before, they know how to encounter all types of disabilities. It's that smile they get, the one that says 'it's okay, I accept your sister and I accept you. I understand.' I hate that smile and it was exactly what Brian gave to me that afternoon. The moment his lips turned upward, I knew it was over.

It was as I was deciding he needed to leave, Christina came limping into the room and looked at Brian. He put on a dorky smile and knelt down to her level. "Hey Christina. How are you? I'm Brian. It's nice to meet you," he said in a calm even tone that had more bubble and prep to it that I had ever heard come from his mouth before.

He was talking to her like a 3 year old and Christina knew it; she smacked him and turned to my mom. "Clue please."

I faked a laugh and announced it was probably a good idea to get Brian home. As we drove back he told me all about his summer camp adventures, how my sister seemed like a lot of fun, and reassured me he had no problem with my sister being disabled. I wanted to slap him. As much as I feared being rejected because of my sister, I didn't want to be reassured that I was still wanted. I just wanted him to shrug and move on, to go on his business and talk about lacrosse or whatever else he was into because saying that he was okay with the disability only sounded to me like he wasn't.

When I dropped him off I turned my head when he tried to kiss me. I told him maybe this wasn't a good idea. I had fun, but maybe we were better off as friends. I could tell he was

hurt, that he thought he made it all better by saying he was okay with my sister and had no idea he made it worse.

20. BIRTHDAY

I forgot my sister's nineteenth birthday. I forgot until my mom called to remind me. She told me to call my sister, but I didn't see the point of giving a birthday call; Christina doesn't use the phone. She doesn't understand the concept of time. When I come home from college, she will give me hugs and want to spend the rest of the day with me by her side, but the excitement quickly fades.

My mom believes that Christina has no concept in time as in she can't tell the difference between a day a week and a few months. There is no reason to suspect otherwise since she doesn't know the days of the week and cannot count.

At most, Christina understands the concept of weekdays versus weekends, but more as in she knows if the bus didn't come in the morning then there is no school. She becomes completely disoriented and frustrated during the summer, unable to understand why she doesn't have school. She'll throw tantrums in the morning when we tell her there is no bus and throughout the day bite her hand, stomp her foot, and throw things because she wants her usual school routine back.

When it comes to me being away at college, she mostly understands only because Steve goes to college in an episode of *Blue's Clues*. The episode is Steve Burns last time hosting the show and describes how he is going away to school to get some knowledge and learn about the planets. From this episode onward, Joe hosts the show and Steve only comes back every now

and then for a visit. For some reason, Christina is able to understand the concept of going away to college because of Steve.

Yet while I'm away, calling Christina on the phone is somewhat pathetic. I'm one of those crazy dog ladies that ask to have their puppy put on the phone. I talk in a loud tone in a way that makes me seem like I was the disabled one in the conversation. I speak in the way I hate, a cute baby voice as if Christina is a puppy.

Though, she does respond in the same way: heavy breathing into the phone and after a couple minutes of pleading from me: "hiiii Christina. How are you? Are you good? Are you being a good girl for mommy? I love you. I love you. Can you say I love you?"

She will give a breathless, rushed "Hi checka I love you."

On her birthay, the conversation was the same. As my mom placed the phone to Christina's right ear (since she is deaf in the left one,) I started up my baby talk in a plea to get Christina to say hello. I ask her about her birthday and even sing the *Blue's Clues* version of Happy Birthday.

"She's smiling!" my mom told me. "She's smiling really wide, but she's just being shy."

I don't know why the phone gets such a different reaction from my sister than when I speak to her in person. Of course when I sing her the Happy Birthday song, she always smiles her toothy grin that squints up her eyes and she wrings her hands excitedly, but on the phone her excitement is so much more surreal. I suppose its because when I am home, I never talk to her on the phone; there is no reason to. I don't need to call home to say hello when I am going to be home in a few hours. I don't need to talk to her to see what she wants from the grocery store.

The phone was our only interaction for months at a time when I went to college and the fake emotion twisted my arm when I was trying to say something like happy birthday. I want to

show I love her, that I care it's her birthday, but at the same time I know this is not how I would be wishing birthday wishes to anyone else in my family or even to my friends. She isn't my pet, she's my sister I love and care about.

But, I have to think about my phone call and how I don't care about today being her birthday; I don't have that same special feeling of wanting to go out to celebrate. Though Christina is nineteen, one more year of being a teenager, I don't feel as if she is any older. It's only when I look at pictures do I notice that she has grown older throughout the years. When I look at her, I feel she has never aged because of her small frame. When I look at her, I still think of her as a twelve year old because she looks like she's twelve years old and acts even younger. It's so hard to celebrate time when it seems so static; she is the girl that never ages.

When I think about her birthdays, I mostly think that with each birthday she is defying the doctor's orders. Though my mom has never come out and directly said it, I have a feeling that the doctor's once told my parents that Christina wasn't going to live past a certain age. They didn't believe she would ever walk and talk, so it makes me feel as if they had no other hope for Christina as well, specially with her grand mal seizures on a regular basis.

Yet Christina has lived through all the seizures and the surgeries. She learned how to walk and how to talk. She can feed herself when she is not being a stubborn brat and insisting that Daddy feed her. She has overcome more than I even realize because I never think about these things. I only think that she is Christina and how terribly awkward I feel trying to speak to her on the phone.

Tonight the whole family is over for my sister's birthday. My mom told me she spent all morning making meatballs from scratch with homemade sauce she jarred with my grandma because my grandma passed away less than a month ago. It's the first family gathering that

we've had since the death of my grandma. My older cousins had been too scared to visit my grandpa, too heartbroken to step into my grandparents house which we used to spend every Sunday together eating pasta and meatballs. So my mom decided that tradition couldn't be stopped because of our grief and what better way than starting it again by celebrating Christina's birthday. The party was at our house this year and when I called, I was put in speakerphone as they sang happy birthday and asked Christina to blow out the candles (which probably resulted in some spitting then the 6 year old twins blowing out the candles for her.)

It was nice to hear family again and to know that it was for Christina. Though I can't seem to talk on the phone to her in a normal way, I like hearing everyone talking to her and making her feel loved. I wanted to be there and love her too.