

Bubble Wrap

“Bubble wrap.” Don’t those two words bring forth fond memories for the majority of us? Perhaps it’s the fun of popping the little bubbles over and over, or the satisfying “pop” sound as you finally manage to squeeze the bubble just enough to be triumphant against it. Some people like to do it slow and steady to really soak in the pleasure of popping those bubbles, while others prefer to go as fast as possible. Maybe some of us don’t like to admit it, but isn’t there still some sort of childish pleasure we feel when we receive a package, and it has that old school bubble wrap that can still be popped? That makes us sound old; we’ve been living on this planet long enough that someone out there thought it was a good idea to invent some sort of un-poppable bubble wrap. Talk about a party pooper.

I’m going to be honest here, now. Hearing those words don’t bring me a rush of childish joy. Yes, I, too, enjoyed popping bubble wrap growing up. However, it was always with mixed emotions. In the back of my mind there was the echo of words that I heard starting shortly after I turned six years old, “I wish we could wrap you in bubble wrap.”

Sounds innocent enough, right? It was always said in a loving manner. It stung, though. Still does. I heard it from my mom, my grandma, my uncle, my dad. You get the gist of it. My family that loved me wanted to wrap me in bubble wrap, and after all of these years I still hear the chorus of their voices wishing that upon me whenever I hear or see bubble wrap. A whirlwind of emotions still consumes me: happiness, anguish, shame, frustration, anger, disappointment, humiliation, disgrace.

At this rate, you might be saying to yourself, “It’s just bubble wrap! What the hell is wrong with you to feel all those ridiculous emotions?”

It is called, “Osteogenesis Imperfecta.” Talk about a big, scary, word. I can break it down for you, though. “Osteo” means bone. “Genesis” refers to the origin or formation of something. You can just knock that additional “a” off of “Imperfecta” to just have “imperfect.” What does all of that mean? The formation of bones are imperfect. I received my diagnosis later on in life than most, and it was thanks to the insistence of my mother that something was not right with me. She was certainly right. I’ll get to that later on, though. Osteogenesis Imperfecta (let’s call it OI from here on out) is also known as “Brittle Bone Disease.” It is not “Osteoporosis” which is also thought of as brittle bone disease; the difference lies in that one is born with OI, but osteoporosis is caused by various factors in life, such as growing older, poor nutrition, etc.

OI is a genetic disease, and most of the time it is passed down through families; however, sometimes it can be a spontaneous mutation. I was that spontaneous mutant, as far as my family is concerned. The majority of cases affect either the COL1A1 or COL1A2 genes; I know, I know, more big scary terms. Both genes affect the proteins that form collagen, which is needed for connective tissues. Collagen also is needed to strengthen bones. There are several different types of OI (nine have been identified thus far) and it ranges from mild to severe.

Osteogenesis Imperfecta doesn’t just mean you break bones easily, however. Some people may have blueish-grey sclera, since the eyes are also reliant on connective tissue (it’s a little known fact, but due to the collagen being defective, the sclera is thinner and thus the veins underneath are more visible, thus giving the color), and some

people may have poorer eyesight and their eyes may protrude some. Muscle tone may be poorer, the spine can be affected (curvature, degenerative discs, etc.) poorer hearing leading to hearing loss, respiratory and heart issues, short stature, bone deformity, and loose joints may also be symptoms.

When I was a baby, I had one of the glaring signs of OI; unfortunately, it was (and still is) not a well known disease. My grandmother used to say, as I was told later on by mom, "She has the prettiest, bluest eyes!"

She was not referencing my irises. No, she was talking about my sclera. While my sclera are no longer as blue as they used to be, I had the tell-tale vivid blue sclera when I was a baby. My parents did not know what that meant, though. I was a sickly child, but I was still called by my parents their little "miracle child." They had me later on in life, although they had tried desperately to have me. My mom saw fertility doctors, since she had difficulty conceiving. In fact, my parents had just about given up entirely- my mom actually applied for a cat breeding license, since she figured that if she could not have a baby, she'd just focus on cats- before they got the news that my mom was finally pregnant.

It still was not a peachy pregnancy, though. My mom received a false positive that I would be born with Trisomy-18, which is a debilitating and oftentimes fatal disease; most do not make it to birth. My mom also nearly suffered a miscarriage; she had to rush to the hospital because, after some quick research that she had done, she learned that she was dangerously low on progesterone. After that, she had to receive a shot of progesterone that my dad administered to her every single day to carry me to term.

When I was finally born, I suffered a lung collapse. Yet, against all these odds, I lived. My mom still refers to me as her little “miracle child.”

I suffered my first official broken bone at six years old. I had wanted to be an ice skater after I watched the Winter Olympics, and had been invited to a birthday at an ice skating rink. My mom signed me up for ice skating lessons, and I was so excited. I could finally learn to skate! I had already been a dancer for a few years, and I loved that. I viewed it like dancing on ice- I mean, how cool is that!? Not only that, but I seemed to be good at it, based on that birthday party and the start of the lesson.

Everything was going so well during my lesson, until a girl in front of me fell on the ice. I had been following behind her, and when I watched her fall, I realized I had to do the proper skate brake so I wouldn't hit her. I accidentally placed my foot too far back, though, so I spun and ended up falling on the ice. The teachers were too busy tending to her, though. I was there lying on the ice for quite a while, and my mother could not reach me. She had witnessed it all from the sidelines, and she could not get to me. No one was coming. Finally, someone realized that I, too, had fallen. They got me off the rink, and I was in so much agony. An off-duty fireman whose kid was also receiving a skating lesson actually carried me out to my mom's minivan because I couldn't walk. It was nighttime, and my mom had to rush me to the emergency room. I was in the backseat in pain, and my mom was speeding and crying because “her baby” was hurt. She actually was pulled over at one point, but when the officer realized why she had blown the stop sign by the hospital, he let her go.

The hospital was terrifying for little six year old me, and I received my very first cast. I had a spiral fracture of my left tibia, and I had broken the fibula as well. The very first

cast was only a preliminary one, however, and they had to saw that one off to put on the proper one. I still vividly recall that saw and how utterly horrifying the saw was. Saws for cutting through casts are loud, and this one became so hot during its use that it burned me. The new cast went all the way up to my groin. It was so big, and heavy, and hot, but it was at least in my two favorite colors at that point: purple and pink. It was this break that was the second sign that something was not right with me. Typically, children heal very quickly. It took me over a year and a half to recover from that break. I could hardly move in that cast, and initially my mom even had to carry me or push me in a chair to the bathroom. I couldn't shower because of how huge the cast was. It was such a relief when I at least could get the smaller blue and green cast that only went up to my knee, although I was still petrified by the saw. That one, at least, did not burn. By this point in my life I had become pretty stellar at using crutches and a wheelchair.

I missed the majority of my first grade because of this break. My teacher was kind and actually came to my house to tutor me since I could not go to the public school, so I did not fall behind. My friends did not entirely understand how devastating it was to not be able to go to school; I oftentimes heard, "You're so lucky!"

I was not lucky. I was in pain. It was embarrassing, needing to be pushed down a hallway in my own house in a little pink chair. My grandfather had built a little wooden ramp to the front door since every single way into our home had stairs. It was embarrassing being pushed up that ramp in a wheelchair, and then being transferred to the pink computer chair since our home was not wheel-chair friendly. It was embarrassing during the first part of my break needing to sleep next to my mother since I needed help to go to the bathroom.

My second break occurred during third grade. I lived in Central New York, you see, up until the end of eighth grade. New York is known for the amount of snow it gets, and unlike Kentucky, school does not cancel at the mention of snow. No, we might have snow banks that are well over six feet tall and it might be in the negatives, but we'd still have school. I was all decked out in my snow boots, and the bus was dropping me off at home. The thing about snow boots is that they're nice and sturdy, yet when I stepped off, my ankle gave out. I fell in the snow, and the bus driver had to honk loudly and roll her window to holler for my mom, who had just opened the front door for me. I could not get back up. My mom came out, and helped me. I had broken my right ankle, and thus I was out for the rest of third grade. That cast was a pretty blue one. This break also took a long time to heal, but not as bad as my first. Once again, my friends thought I was "lucky" since I didn't have to go to school. I don't think they quite understood, though, since I had a tutor come to my house to ensure I would not fall behind. I still learned my math facts, and I still learned my history and my spelling.

Fourth grade I broke right arm. It was a mixture of things, I think, that caused the brake. Back then, I liked to ride bicycles around my neighborhood, and this one time I had a pretty stellar crash. I had the coolest bike, it was by Orange County Choppers and it had an extended front tire. It was my pride and joy, and I loved to go speeding down the one hill. I was a little speed demon. One time, though, I didn't brake enough during the turn at the end of the hill, and I crashed the front end into a fire hydrant. Needless to say, I went soaring over and landed on my arm. I wanted to cry, but I didn't, since my dad was right there. He was worried about me, but I insisted I was fine. I even said, "Don't tell mom!"

My arm hurt and was tender, but I hid it well. I didn't want mom to worry. Things were seemingly fine despite the pain until a week later I fell walking down the little sidewalk in front of our house to our driveway. Mom was there with me, and the pain was so unbearable at that point that I lost it, and even confessed to the bike crash prior. I had a broken right radius and ulna in my arm, and this cast was hot pink. I missed some school, but I was able to go sometimes.

My mom was beginning to question at this rate whether or not things were all okay with me, since it seemed as though whenever I fell, I either broke or sprained something. (Yes, I did have sprains scattered in here or there, but I won't toss all of those lovelies at you as well.) It was not until my break in fifth grade that she was listened to by the doctors.

In fifth grade, I broke the top of my left humerus; the humerus is one of the strongest bones in your body, and it is incredibly hard to break. Yet, I managed to do it on soft, muddy ground. See, it was during gym class. We used to play Capture the Flag, and I was always pretty damn good at it. No, I was not the fastest runner, but I was a great teammate. I had just captured the other team's flag, and I was running for my life. I remember that one of the other team's players were coming after me, but I didn't want to let my team down! I was running, running as fast as I could, but then my foot slipped. It was recently rained, so the ground was slippery with mud. You know those cool baseball slides when they reach a base? Yeah, that was me. I went down, and I landed on my left arm in that slide. I didn't cry, how could I? I was surrounded by my class! It hurt so much, though, and my gym teacher relented by letting me go to the nurse. I walked that field, all the way to the nurse's office, but luckily I was escorted by a friend. I

insisted she go back, though, once I arrived. The nurse knew me well enough by then; she had actually, earlier on in my elementary years, been the one to realize that I had scoliosis. The curving of my spine was due to my (undiagnosed at this point) Osteogenesis Imperfecta. She called my mom, and she came to come pick me up. Mom said later on that, upon seeing the paleness of my face when she walked in, that she knew I had broken another bone.

Here's the thing about breaking the top of your humerus: you can't be put in a typical cast. My break was too high up, so instead I was put into this awful grey and white immobilizer. It strapped around my waist, and held my arm securely there. I missed some school, but you know what else I missed? My fifth grade class trip to New York City. That devastated me. I had missed my fourth grade Albany trip because of my health, and now I was going to miss the infamous NYC trip. Up until that point I was pretty strong; see, I was still involved in dance best I could be, and I had even tried karate several times. I missed some of my own recitals, and being out from karate so many times from breaks meant I never got to move past a white belt. I had even gotten involved in orchestra! I played violin, and I had been good at it. I missed some of those concerts, though, whenever I broke my arms at various points. I also was involved in choir, and choir concerts were always at the same time as orchestra concerts, so I missed some of those as well. I missed a lot of things that I had loved. It began to cause a lot of disappointment in me, from myself. It hurts when you practice for something, only to not get to see your parents' joy during your recital/concert. It hurts missing school, not getting to see your friends, because you're out once again. You don't get to form the friendships that others do since you are absent so much. And it still stung,

being told that you're "lucky" for missing so much school. I wasn't lucky. I was in pain, and I was growing up in goddamn doctor offices.

As I mentioned, it was after breaking my humerus (and no, it was not very *humorous* of me) that my mom insisted they start testing me. Why was I breaking so much, and so easily? See, she had fallen on concrete shortly after I fell on goddamn muddy grass, and she, too, had landed on her arm. As she stated, she was heavier than I was since she was an adult, taller than I was, and she landed on concrete, yet she was completely fine. I was a child, and people claim that children are hardier and do not break that easily, yet I broke one of the supposedly strongest bones in my body on stupid wet muddy grass. She knew that something wasn't right.

I was sent to a geneticist, whom had a skin biopsy done on me. They took a little chunk of flesh from my back, and for the next couple of months they grew the cells in a little petri dish somewhere. I thought that was pretty cool; somewhere out there, they were growing my own cells, and they weren't even attached to me! So cool. It was then that they realized that, hey, *something was wrong*. Mom was right. I was not normal.

They called me back to the geneticist, and he gave me the diagnosis of Osteogenesis Imperfecta. I didn't understand all that I do now, but mom did. It was then, upon learning that I did not have the familial aspect of it, that we learned that I had the spontaneous mutation of it. At some point during my mom's pregnancy, my genes decided to have some fun and mutate, I guess. Now, you might be thinking something along the lines of X-Men at this point, but let me tell you, I was clueless as to the X-Men. I was more of a DC girl growing up, anyways. I found no solace upon learning that I

could not blame some unnamed family member for what ailed me; it felt like it was *entirely my fault*.

I want to make it clear that at no point during any of this did my mother, father, or little sister make me feel awful for my breaks. No, I was the one making myself feel awful. I spent more time waiting inside white doctor offices and rooms than I did inside bright colorful classrooms in elementary school. I was learning about medicine indirectly while other kids were memorizing their multiplication tables. I was looking at x-rays while other kids were looking at the I Spy books with their friends. I felt as though I was robbing my little sister of her childhood; she was only an infant in a stroller during my first break, as she is six years younger than I am. Instead of playing with her toys at home or in school, she was playing with toys in doctor offices while she waited for me during my appointments. You see, my father traveled for his work, so during the work week he was away in a different state. He felt guilt for not being there for my mom, or me, or my sister, but he couldn't do anything about it. We needed the money and the insurance, anyways, to pay for all of my doctor visits.

Sixth grade was a turning point in my life, but it was not for the better. Due to my diagnosis, my mother had a meeting with the school officials prior to my going into sixth grade. I was going to have a 504 plan, which is a legality that means that the school *must* abide by whatever the plan may be. 504 plans are designed to legally protect children with a disability in primary and/or secondary schools should they require a special modification to the typical curriculum. My plan included that I would not be placed into a regular physical education class; we knew that I needed PE, technically, but I would not be safe in a regular gym class. If I fell, I would break. Thus, the plan was

that I would have a one on one version, and the assigned teacher would have me do simple things, such as a light walk, or a recumbent bicycle. Essentially, things that were more akin to physical therapy (of which I had had plenty of those visits by then) would be okay as my version of PE.

Things were going well and dandy until December 10th. My designated teacher decided to place me into the regular class on that day; they were playing aerobics kickball, and later on they may even do rock wall climbing. I was only a child still. Why would I, the student, speak up and out against the teacher? I was scared of being in trouble. I didn't want to be sent to the principal's office! I'd always had a perfect record in regards to that. My attendance may have always been shot to hell, but never once was I sent to the principal's office for misbehaving. I was not about to change that.

Aerobics kickball, as I learned that day, means that there are two teams: the one out on the field trying to catch the balls and strike out the other team, and the team that is the one kicking the balls out into the field. The difference between it and regular kickball? The kicking is nonstop- each teammate kicks it and just runs; there are none of the typical turn takings. You kick, and run as fast as you can. I was out on the field when my fall happened. A blue ball came flying at me, and it struck me. I fell to the ground, and my right knee struck into the cold hard gymnasium floor.

The agony that blew out through my knee into my body was shocking, and I burst out into tears. I was a sobbing mess, in fact. They managed to get me over to the side of the gym class, and the other kids all seemed genuinely concerned for me. It may have been due to the way I was sobbing, though. My teacher insisted to the other teacher (whom was actually more concerned looking than my own) to have the kids continue the

game. She tried to convince me that I was fine. I knew I was not fine. She finally relented and let me go to the nurse's office, and thus I began that slow, horrific walk. It was more of a severe, slow limp, though. That was the other part of my 504 plan that I broke. If I were to fall, they were to leave me there where I was and get the nurse to come to me. I was to not be moved. I limped down to the nurse, and Mom then came to get me.

So, here is where things get to be a little bit interesting. No, I did not break my knee, but what I did do was tear my patella femoral ligament (PFL.) The patella, also known as the knee cap, is held in place by a couple different ligaments. These ligaments are also somewhat connected to your femur and tibia. The ligaments may have strains based on the Q angle of your leg; the Q angle is the angle at which your bone comes in to meet your knee. See, what they did not know at the time is that I had torn my PFL, despite the MRIs and X-Rays that I had done. Apparently, it did not want to show. So, my knee cap was continually subluxing; subluxation is the big fancy medical term for my knee cap basically being a little prick and continually popping out of place. In internet slang, it did not want to stay in its lane. No amount of physical therapy was helping it, and it worsened to the point that it would even pop out of place while I was wearing a knee brace when I was sleeping.

My amazing orthopedic doctor discerned that I would need surgery. After reviewing my X-Rays, she determined that the Q angle that my tibia came in was too severe and it was causing too much tension on the knee, thus causing it to pop out. I would need a Fulkerson osteotomy done; what that meant was that they would go into my lower leg, break the tibia in two places by cutting it, move it over to give my leg a better angle for

the knee, and then screw it in place. The recovery period would be long, and for three months straight I would not be allowed to put even the slightest bit of weight onto my leg, otherwise I would risk shattering the bone. It was during the surgery that my doctor actually found my ligament tear. She repaired it, and I was on my way to three straight months of utter hell. I had the surgery done in March, so needless to say I was on homebound for the remainder of sixth grade. Not that I was having perfect attendance after my fall, of course.

Later on, I needed a second surgery on my leg. In November, I needed a hardware removal of the screws in my tibia since the tendons around the screws were rubbing against it. The pain that it caused from their rubbing was horrible, so they had to come out. That meant more missed school (the surgery was during November) and more recovery time, since the screws' removal meant that there would be two little holes in my tibia. I was in eighth grade during this. Seventh grade had been me in and out from doctor visits, pain, and the growing issue of my spinal problems. We had blamed the long recovery period of my surgery for my worsening back pain. Likewise, we blamed my second surgery for the continuing pain. It was not until I finally received a proper x-ray and MRI scan of my spine that we realized I had Degenerative Disc Disease (DDD.) I was about thirteen when my chiropractor told me, "I've seen 80 year old women with better spines than you have."

My DDD was caused by my OI as well. My lumbar region of my spine (the lower back) was messed up, and it was not from the recovery periods. The pain I had from it caused me to miss the majority of my eighth grade, along with the recovery from my

hardware removal surgery. I had an excellent tutor, however, that ensured that I did not fall behind.

After eighth grade, we moved to Kentucky. I was so excited! A new area, a new school, a fresh start! I was disappointed that my school did not have an orchestra, but that was okay. I'd make it work. Besides, at that point I had already given up a lot of things, like karate long ago, and I had finally given up dance because of my messed up knee. I was finally going to be in high school, and I was ready for this fresh start. I was ready to face the world!

I made it five days. Five days I was able to go to public high school until I was out from my worsening spinal pain. The doctors wrote me out for the rest of the school year so I could see specialists. I was referred to Shriner's hospital up in Lexington, and I saw a variety of doctors. The school sent a tutor, but they were nothing like what I had received back in New York. No, I began to rely more on myself to teach and learn. I started receiving spinal injections to lessen the pain, and I even received at one point a radiofrequency ablation; that's a big fancy term for when they go in and very carefully burn a part of the nerve in your spine that is being pinched. It's to help with pain in the long run. I bounced between Shriner's and Good Samaritan, and it began to get to the point that the nurses in the outpatient surgery at Good Samaritan knew me.

Tenth grade I decided to try homeschool since I was not getting any better with my back. On top of that, a couple months in and my right knee decided to start popping out again. It was nothing too severe, but it was a reminder of the injury I should have never received in the first place. It was during tenth grade that my one disc finally decided to herniate to the point that I needed emergency surgery upon the doctors finding out. It

was terrifying, that day, when I received the news that I would need surgery on my spine. I had had yet another MRI scan of my back, and instead of only my typical doctor walking in, three walked in and delivered the blow. I was stunned. You see, we knew that something was wrong, but what we didn't realize was how bad my L5 disc had truly become. The fifth disc in my lumbar area had started causing severe issues such as incontinence and referred pain down my leg. I knew a new form of embarrassment like no other; I needed to wear pads because I could no longer physically feel when I needed to urinate. My disc was pressing into my spinal cord, and it took that sensation away from me. All I felt was agony, and shame.

It was not even two weeks later that I was receiving surgery at UK hospital. They wanted to operate as soon as possible, because if my disc was not fixed, I could potentially suffer irreversible damage. I had a discectomy done, where they removed the majority of my L5 disc. I had become involved with a homeschool co-op, and they were to have a cutesy homeschool prom; ironically, on the day of the prom (of which I had even purchased the dress, the shoes, the accessories, everything) instead of going and having fun, I was under anesthesia having my disc taken out of my spine.

The recovery period for my discectomy was long, but I still had hope. Perhaps now my back would be all better, and I could return to public school. I enrolled once more, and had it all planned out. I made it two months this time before my spine decided to act up once more. I was out, once again, for the rest of the year. This time I had the tutor, and the school placed me instead on an online schooling. My L4, L3, and a portion of my S1 were bulging some, but it was not to the point of anything they could do. I was told in eleventh grade that, "You'll be living with this for the rest of your life."

By my final year of high school, I was bitter with the world, but it was not from the infamous “senioritis.” No, I was simply tired and angry with myself. The public school did not even bother to have me attempt to return, and I was more than willing to follow along with that. I did not want to darken their doors. They placed me back on the online schooling, and sent the tutor to the house to ensure that I was keeping up on work. I did enroll in the ECU Dual Credit program, so my only form of socialization was during the classes that I took on campus: Acting 1 and Intro to Psychology during the fall, and Latin 1 and Abnormal Psychology during the spring. I still suffered from pain on a daily basis, and it was during my final two school years that I began to sink into depression. My hopes of a fresh new start had been dashed long ago.

I did not attend prom. Nor did I walk the stage when I graduated. No, I simply had my diploma mailed to me. Why would I walk on a stage full of strangers? I did not know anyone, so I was not about to be a stranger amongst the sea of friends and frenemies and all of the cliques that high school had established. I would have been a nobody, and I did not want to put myself through that. At this point in my life I felt a form of self-hatred that had grown to consume me. Somehow, though, despite all of the odds I graduated with stellar grades. I managed to enroll in ECU’s Honors Program once I was accepted to the university.

I thought that college, perhaps, would bring me a fresh start. Maybe now I would form all of the friendships that I had missed out on during high school, and maybe now I would experience a relatively pain free life. I attempted to live on campus for my fall freshman year, but it soured, ultimately. The depression that I lived with, along with the anxiety, consumed me and at one point I ended up hospitalized. The anger and

bitterness that stemmed from my compartmentalized emotions regarding all of the times I had been let down from pain, broken bones, and surgeries surfaced as an eating disorder. I withered away, my depression worsened. I did not know at the time that it was my own anger taking itself out on me. Doctors had continuously told me growing up that maybe my Osteogenesis Imperfecta and degenerative disc disease would not be as bad if I, “lost some weight.”

I did, but it took over. It became my coping mechanism, and the pain never did go away. I still lived through the disappointment. Remember how I said that I had given up dance? I had learned during my fall freshman semester that ECU had something called “Dance Theatre.” That sounded like so much fun, and I wanted to take a part in it! I missed dance, so terribly much, and I viewed it as my chance to embrace it back in open arms. I went to the tryouts, and I had even found my old dance shoes that still fit. It was my moment, and I was going to give it my all! I felt an excitement that day that I had not felt in a very long time.

That day ultimately became the trigger for my eating disorder to worsen, and for the depression to utterly consume me. It was during the routine for my very first tryout, and my right knee snapped. The exact same one from sixth grade; the initial injury that should have never even occurred. I almost went down to the ground entirely, but luckily since the tryouts occurred in groups, no one witnessed it. I excused myself as dignified as I could, and I limped outside of Weaver building; those stairs were so excruciating, but I was not about to ask for help. I managed to limp around to the other side until I had to lie down on a bench in front of the building.

It was a Saturday, and it was still summer at that point. A campus cop happened to see me lying there on the bench, and he came over to me. He most likely thought I was some passed out druggie, or maybe I was down from heat exhaustion; regardless, he came over to check on me, and I relayed to him what had happened. He ended up calling the ambulance for me, and I called my mom finally to tell her what happened. She met me over at the hospital, and while I was fortunate enough to have not torn anything this time, I still felt the shame, humiliation, and disappointment. I certainly had not wanted to cross off an ambulance ride on my list of, "Things I Do Not Want To Do."

Needless to say, my hope for Dance Theatre was snuffed out. As I mentioned, the depression utterly consumed me at that point, and I became suicidal. Combined with the worsening eating disorder, and I wound up later on shortly after my eighteenth birthday held for nearly 24 hours under psychiatric watch with potassium being pumped into my veins. Talk about riveting fun. I still had not made all of the connections that I have now in my mind as to what caused my eating disorder, and I thought the depression was just me being an angsty teenager. Don't we all have that phase?

I ended up breaking my housing contract shortly after that fiasco, and I never did return to live on campus. I did not even last a full semester. Luckily, I lived close by, and I abided by the whole living with family deal. It was a good thing, too, since right before the beginning of sophomore year of college I suffered my next break. This one, perhaps, wins the most ridiculous story award.

I thought I would be an oh-so-helpful daughter and go upstairs to get my mom a fresh gallon of milk; see, we live in a two story, and I'm the basement loser. We keep the additional milk jugs on the second floor in a mini fridge so we do not overcrowd the

main fridge on the main level. So, I knew that we were out of milk, so I decide to go upstairs and get her some so she would not have to go up a full flight. The thing about my family is that pain, unfortunately, runs through it. Whereas I have OI and DDD, my mom has rheumatoid arthritis; of course, thanks to all of the breaks and surgeries I have endured, I have arthritis in all of those spots. My mom and I joke by saying that we can always predict the forecast based on our pain levels.

Anyways, so I get the jug of milk, and I come back down the stairs; only, I accidentally missed a step. I end up falling, well more like sliding, down the last few steps and I happen to land *hard* on my tailbone. I looked like a damn idiot. The awesome part about all of this? I held on to that stupid jug of milk the whole damn time! You best believe I did not spill it on top of everything. I sat there for the longest time just stunned, though, by the pain radiating throughout me. My mom finally convinced me to take me to the ER, but they apparently did not know how to listen to patients that day. They did not even scan the right part of my back. It was not until about a week later when I saw my spine doctor that I learned that I had, in fact, broken my coccyx. That's the fancy medical term for your tailbone.

That was my last break, so for the past two years I've been going pretty strong in regards of breaks. I still suffered from depression and anxiety. The eating disorder was still there, and I did not seem to catch on that it worsened whenever my pain worsened. I never really did face all that I had experienced and all of the letdowns I have lived through. I did not want to face the arthritis that had settled in my bones in multiple areas. I did not want to face the discs in my spine that were bulging and would not fix. I did not want to admit that I was not okay.

One of the things that always made it difficult to admit that I was not society's ideal of "normal" is that I still appeared seemingly able-bodied. I am 5'6" during the days that I can stand up straight; I have a feminine appearance, and some days I can walk alright. I can stand. There is a notion throughout a lot of society that to be disabled you must be in a wheelchair, or using a walker/cane/crutches, or perhaps you have a guide dog for sight or hearing. If you can stand and nothing is immediately pointing toward disability, then it is surely all in your head. There is also a notion that younger people cannot have a disability. I cannot even begin to count the amount of dirty looks and stares I received from adults growing up whenever I needed an electric wheelchair in a store because I could not walk. Surely I was some annoying child/teenager that was goofing off; there was nothing wrong with me.

The shame in my seemingly able-bodied appearance worsened as I received my driver's license and had the disabled parking plate on my vehicle. It is not that I was initially ashamed of needing it; I cannot walk those long distances most days to whatever building I am needing to go to. No, the shame began whenever I would park on campus and I would get out, and I would receive those stares like I had before; some 20-something year old getting out of their car, and nothing obviously wrong? Surely I stole that plate and parking pass, or maybe I was some lazy loser borrowing their parents' car and wanting to capitalize on having parking closer to the building.

Shame grew, too, as I would receive criticizing stares for my limp. Maybe I was seeking pity, or maybe I was being dramatic. *What was wrong with me?* I would try to walk normally, but the pain would only worsen. I did not want to limp. I did not want to draw attention, no, I wanted to be invisible. I wanted to fade. That most likely

contributed to the eating disorder; maybe they would not notice me if I disappeared. They would not notice the pain coursing through my body. No one ever looks at your eyes to see the agony burning there. No, they only eyed up your body and judged you for seemingly being okay. I, instead of being physically wrapped in bubble wrap, wrapped myself inside my own mind and let no one in. I did not socialize. Everyone judged me, I could feel their eyes, and I wanted nothing to do with them. I shut and locked myself away for my sophomore year, and part of my junior year. No, I would only dedicate myself solely to schoolwork and achieving As.

It was not until spring of 2017, when I should have been starting my second semester of my junior year, that my life crumbled once more. My eating disorder landed me in the hospital for a week because my heart almost gave out. I had to leave school for the entire semester, and this gave me plenty of time to self-reflect and figure out what had happened to me. What caused all of this? I found the rage that had been boiling inside of me toward myself for a very long time. I found the sadness, and bitterness, that I had not wanted to admit. I lived my life saying that things were “fine.” Life was fine. I was fine. *Only, I was not fine, and had not been fine for a very long time.* It was hard to admit that.

I have grown to be accepting of my circumstances now, though. I do not hold bitterness toward others, even if they judge me immediately. I would much rather discuss my problems with them and educate them than be angry toward ignorance. I learned to let go of all of my missed opportunities and lost hobbies. I learned to let go of dance, and ice skating, and everything else that I was let down on. I learned to embrace my Osteogenesis Imperfecta, and all that has come along with it. I became, without

myself even noticing, more empathetic toward others. I still feel sadness when I have to miss more school, and I still feel guilt for putting my family through so much. I did not want to have grown up in doctor offices, and force my mother to always be there for every single appointment. I did not want to have seemingly taken my sister's childhood away as she spent the majority of her time in doctor offices in the waiting room as well. I did not want to put any of them through that, yet, that was out of my control.

My mother still calls me her miracle child. She tells me that it is okay that things turned out the way that they did, and you know what? I am gradually, oh so gradually, learning to accept that. I have already accepted the pain, and I do my best to push through it. I also have learned to have accept the circumstances that I was dealt. I am fortunate. I have a family that accepts me, and I now have people that accept me as well. I no longer constantly run away from others when the thought of socialization appears. I have accepted that I am not as able-bodied as some people, and I have learned to teach those that may not understand my condition. The thing to ultimately take away from disabilities, though, is that they are individual; others with Osteogenesis Imperfecta will look and act different than I do, and perhaps they broke far more bones than I have. They may have experienced depression, or anxiety, or something else, or they may not have had any of that. We are people, too. We are individuals with our own stories.

I may not have been wrapped in bubble wrap despite my fragility, but that is okay. Whenever we receive a package, don't we take it out of the bubble wrap, anyways? I have learned to show myself instead of hiding away; I do not need bubble wrap.