

*A Life of Pain and Love* by Jessica Coviello

This story is a work of nonfiction.

Everything is true and really did happen in my life.

For all of my friends and family

I don't know where I would be without all of you.

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## **Early Life**

I was born on the 17th day of July in the year 1999. I weighed 8 pounds and I was a beautiful Italian baby; as so I'm told. I had jet black hair and I was a chunky monkey. I looked nothing like an Italian when I was born but I was insta-famous. I heard stories that people would always look in the window where all the babies were kept and just say

“look at that baby over there, she’s so beautiful”. I think part of that saying was because I had a full head of hair. I do not know if these stories are true but if they are, I thank you. The minute me and my cousin were born; a week apart, the hospital switched our records; for a brief minute. They thought that my parents had him and his parents had me, it was an easy confusion. We are both italian, were family, and we were born in the same hospital. That story always cracks me up; I just wish that we kept more contact with each other because him and his family are one of the good ones. My brother came not long after me, he was born in 2002; I was 3 at the time. When my parents brought him home, I was very upset because I had to, now share my parents with somebody else.

As you can probably guess, I did not know any better at that age; I thought he was a girl so I gave him one of my headbands to wear, I thought he looked very pretty. When my parents saw, they took it right off of him and they did not get a picture. He had some hair, and at that time, I did not know what a boy was; really. To my surprise, I did not know why they took it off but I just forgot about it and went to my room; which I shared with HIM. When I went to preschool, I LOVED it so much! I went to the Ripley right down the street from where I live. I made three great friends when I attended, they were triplets; I was so shocked when I first saw them. I was like “wait you are all sisters and you look alike”. I wasn’t a very smart kid when I was young. The best part about preschool was when I got to take home the class animal for the week; and yes, it was stuffed. When I went, we got Curious George and when my

brother went, they got Elmo; I was so jealous. Even to this day, I love Elmo. At that stage of my life, I was a weird, innocent, healthy and extremely happy little girl, I loved everything. If I was to look at my younger self today, I would say “why are so happy” and “what could have made you smile that much”? Back then, I was a dancer, and a pretty good one. I used to dance at an academy close to the Ripley. I loved dancing, it was fun and I did make a friend or two there, it was awesome; we even had recitals where I would show off; a bit.

I started elementary school, and believe or not, I had a lot of friends, like a lot. I went to school at Lincoln Elementary. I loved kindergarten, my teacher was so kind and caring, she was amazing. First grade took a little more time to get used to. My teacher was very strict, and that was good. I was the queen of spelling bee's, I beat my whole class, I was just that good and I had a photographic memory, I got straight A's in elementary school, it was amazing. Second grade was even tougher, my teacher would make us read every day in a circle and we had tests. Surprisingly, I did good in wellness and in all of my subjects, I don't know how but I didn't question it.

## Falling ill

When I started third grade in October of 2008, I was assigned a fantastic teacher for homeroom, I walked in with the normal attire, a pencil, a book, and I carried a backpack. Once I found where my desk was, I sat down and looked to see my new room. My eyes went a little wacky and I was not to sure why, so I put my head down on my desk and when it was time to circle up and pick a book, my teacher called me but I didn't hear her, I wasn't getting up, I just stayed laying on my desk. I blacked out, I do not remember much; all I remember is that someone took me down to the nurse and I did not leave until, maybe half into the day. When my mom came, I complained that my head hurt and I was very dizzy. She took me to see a doctor, and he checked me out, but found nothing wrong with me. All he said was that I had a virus and it would go away within a week. That was it, we just left and I got a good night sleep.

The next day, my dad took me, my brother, and his friend apple picking at Smolak Farms in New Hampshire. I was fine at first, but then something weird happened. We were in the field of red delicious apples and I was walking straight until my eyes starting going and then my feet were turning and turning; I was not quite sure what was happening until I fell into the grass. My dad found me, immediately dropped everything and took me to Mass General in Boston. He called my mom beforehand, so she would drop everything and rush over as well; she was working at the

time. Mass General was where they got the answers that they were looking for. My neurologist was the one who told them. He said that I had OMS. \*I never found out how I got it\*

That was the day when my life changed and never remained the same.....

When I was eight years old, I was diagnosed with OMS. I had a tumor on my right adrenal gland that affected me in so many ways. OMS stands for Opsoclonus Myoclonus Ataxia Syndrome. It is a very rare neurological disease that happens more to infants.(19 months) It is a 1 in 10,000,000 case, the disease starts with fast eye movements(dancing eyes), then you start falling, and you begin to lose all movement in your body. I was in three different hospitals in the span of 6 months and in a wheelchair for 3 years. The hospitals that I went to were Mass General, Franciscan, and Spaulding Rehab. I was comatose for several months, since no one really knew what was wrong with me. My doctors and my nurses would come into my room every day offering me new medications.

I needed a lot of one on one help, I was really out of it. Thank God for my neurologist, and in finding my tumor the way that he did. Once they found it, they removed it, I needed a bunch of surgeries, I did receive a lot of cards and get well soon gifts from my friends at school and some teachers but seeing them would have been a far

greater present. Don't get me wrong, I am sincerely grateful; they didn't have to do that. I had a lot of family members come by and visit me but I was completely out of it. I felt nothing, I could move nothing, I was plain in simple, out cold.

Half of my time in the hospital was either being comatose or being in a wheelchair. I did however, have a walker that when I was somewhat strong enough, I would use that and walk a few steps a day. I had to move around all that I could during those days and try not to stay sitting all the time.

In my time at Spaulding Rehab, they would bring in therapy dogs to comfort the patients, it helped us find our senses. I remember loving that time when the dogs would come in, I would love to pet them, to get their sense of smell, and love. The dogs were the happiness that I'd get before each surgery I had to have. I would have a lot of nausea afterwards, I would have new doctors come in and give me a new treatment, as well as medicine. I had a lot of Chemo and IVIG all rolled up into one. I eventually got to go home but with a few setbacks. I could not go back to attending public schools so I did get pushed back in the third grade.

## Going to Beverly

I redid my three years at a school called The North Shore Educational Consortium, it is a school up in Beverly. It was a really good school for me at the time. They not only helped me with my walking, but also with schoolwork. Everyday, I had my O.T, my P.T, and my Speech therapies. In O.T, I had to work on little things like picking up blocks and counting on my fingers, In Speech, I had to work on talking as little as saying hi and bye. My physical therapy was the hardest at that time, seeing as I could not walk, they both had to physically take me out of my chair and put me back in. I had little to no function at that time and they also had me do the treadmill, but I mean she did help me by getting on behind me to make sure I did not fall. The only thing that I wasn't to keen about was the fact that I had a gait trainer, it really messed up my arms. My P.T appointments would be scheduled everyday for an hour. I really enjoyed getting to know them but I could've done without the treadmill.

To clarify, I started off my days with Physical Therapy in the mornings for an hour which was followed by Occupational Therapy in the afternoons, and Speech to finish off the day. I worked on my legs and arms in P.T, I worked on my hands in O.T and I worked on my vocal skills in Speech. They were all hard, that is precisely why I said I hate my therapies. My therapy was every day and I got very tired of it all. I had to improve myself, which was

the hardest because I couldn't walk, I couldn't talk, and I barely could see. I had a very raspy voice due to all of my surgeries.

My class and I would go on field trips every Monday. We would go to the grocery store for our cooking class, we had to find the ingredients at a reasonable price. Cooking was my favorite class. The main goal was to work on fine motor skills and build strength in our upper bodies. We made all types of food, but mostly baked cakes, cookies, anything that involves batter. That school was great, I loved all of my teachers, my classmates, and my therapies, as painful as they were. They all really helped me; I met my favorite person there, she was the main teacher. She would always tease me but I knew in the end it was never intentional. She would do it because she knew I was not my illness. I always looked up to her, and though she was the one to give me all of this work; and she did that because she knew I had intelligence, she saw something in me; and apparently she had to joke around with me to get it through my thick skull. She was my favorite person there; at that time. I had a lot of favorite teachers at that school, some were aids, and some were students. We had a daily schedule every day so it wasn't like work work work, we had our fun. The agenda consisted of a walk, snack, library, for me P.T, Speech and O.T; I mean we all had it but all of us were at different times. I got a lot of free time considering; and I would do my best and try to make cards or friendship bracelets. I did

however make a friend in that school, he was a teacher as I remember, he used to if no one else could; take me to the bus or get me from my therapies or just help me with my skills; like making friendship bracelets.

The days that I was home, I would either be in my bed that Spaulding Rehab gave me or crawling on the floor. The bed that they gave me out of the hospital had a net on the sides that would zip up so I couldn't fall out; and believe me that happened, quite often. I had tons of fits/episodes and when I needed to blow off steam, my parents would put me in my bed and zip me up. I would have episodes all of the time, I remember trying to get up when I was crawling and got so frustrated that I banged my mouth into the kitchen floor and broke a tooth. My episodes were awful, I had no idea that I was hurting the people around me, even saying bad words. I was fully out of my mind set, I had no idea what I was doing.

There was one day, I was in my wheelchair at Mass General with my aunt and my mom. I had just finished my chemo treatment and my mom was going to drive me to school. We were taking the elevator down to the lobby, and I screamed out my first word since I got sick; "FUCK". As I said, I had no idea what I was doing, I had no idea what came out of my mouth. I went through so many treatments in my life that I was just focused on one thing; the pain and not my surroundings. That day, I was the worst I could be, my mom got stuck in traffic right near my aunt's house, I got so aggravated and wanted to go right to school that I made my aunt walk the rest of the way to her house. I was

late to school that day but my point is my illness made me so bad that I didn't even care. I had little to no emotion, I had to learn everything from the beginning, it was like I was a baby all over again.

But, hey, I'm getting way to ahead of myself here....

## My Hero

In my first few days at Mass General, I got three different rooms, "hey I needed to be as comfortable as I could get". They brought me in on a stretcher and seeing as I could not help at all, I needed 3 doctors on either side of me to help transport me to my room. When we all got there, they rolled me onto my bed, "that hurt" At first, I had no idea where I was, I was faced down; ahh so that's why. They turned me over and what was awesome, they had a bear waiting for me on my bed, it was a huge bear; but don't get to excited, it was a coughing bear. I had him if I needed to cough or barf, I had him almost every minute of the day, They did however, give me a cough pillow.

While I was at Mass General, I would get lots of MRIS and lots of CAT scans for my brain. "O yea the tumor affected my brain", I had no movement of my body when I got admitted. My only visitors at the time were my parents and my brother, he was really young at the time and he didn't really know what was going on. My mom and dad

would always put the movie Eragon into the dvd player, so I could watch it on the television with them. I was forced to watch it; I hated that movie. I don't know how much I actually saw because my eyes were going nuts but I guess it was good. We watched it over and over again; it was either Eragon or Mary Poppins. I was so sick of Mary afterwards. Day by day, it was a tradition for my meds, usually crushed up pills in applesauce or liquid since I could not swallow pills.

After my meds, they'd want me to go outside and be active to the best of my ability. Considering what was going on with me, I was not; at all, in the least bit active. My mom took me outside in my wheelchair, she was the one walking; obviously. My eyes were open but my mindset was sleeping. When we got back in, I would go back to my room ready for bed, but no; my nurse came in and took me out to try and do some arts and crafts, she was the one who gave me a guitar for my birthday, as I remember it. She would always call me a diva and I think she did so because of how sassy I was. (I still am.) My episodes were far from over, I would get them out of the blue, my intentions to do things were all over the place.

At times, when I wanted something; I would kick my nurses, I didn't know what to do, I couldn't talk, I couldn't see them, and I could not walk. I was very frustrated; as you can imagine. I spent a total of 2 months at Mass General, when I moved, the paramedics took me to another hospital instead of my house; I was so depressed. They

took me out of the hospital in a stretcher, and moved me into the ambulance to go to hospital #2; Franciscan. Now, I went to this hospital for about 2 in a half months, I fell into a coma at the time. I was comatose for several weeks, I did get out and when I did, I would have calls on the telephone and I would do my best to answer them but my voice was very raspy. I remember, one day at Franciscan, I called my dad and because he was already coming with my brother and cousin; I got up enough voice to ask him to get me McDonald's, I really wanted that donkey toy from Shrek; not even the food. (I know, crazy right?)

Half an hour later, they came and I had a huge smile on my face. Especially, when I saw my cousin AJ. My eyes would always shoot up when I saw him, which is very rarely. When my dad came to my bed to give my kids meal, I see my burger, and my apple slices; I was so annoyed with him, I wanted fries, not apple slices. But what I really wanted was my toy and I didn't see it; my cousin had it the whole time. When I saw my toy, I left the food for my cousin and my brother.(you're welcome, BTW) My dad would always tell me I had to eat but with all of the steroids that were in my body at the moment and all of the chemo that I was on, all that food would do to my body was make me throw up. I did eat, probably a bite; but I rarely ate when I got my treatments.

Throughout, the visit with them, I was laying on my bed; completely out of it. The only voice I was aware of was my cousins. I loved when AJ visited me, it always brightened up my day. He was the highlight of my life when I

got sick, I would always cling onto him. Another time, my grandma brought him and my brother to the hospital; they wanted to see me. They all said hi to me, but the part that I remember was my AJ and my brother, Matthew climbing into the bed with me. I was holding onto AJ for dear life, I did not want him to go; It was depressing being there alone. They stayed with me until I fell asleep. All I had was my doctors and my nurses, I was still getting used to them so my surroundings were not familiar. I was at a new hospital, new care, and the staff was alright. When I woke up, I was surprised; I saw a nurse right in my face with my medication and my wheelchair, getting ready to move me to the breakfast room. This is all my opinion, but I hated being woken up like that; even if I was sick.

The next hospital I was moved to, by stretcher; of course was my favorite. Spaulding Rehab, I don't remember if I had the nurse who called me a diva here or Mass General, but she was a big reason as to why those hospitals were my favorite. When I got to Spaulding, I was moved to a big room with a huge TV and once again, my routine did not change one bit. I forgot something big here, I had no function in my body; Which meant that I could not go to the bathroom myself. I did have a bedpan at times but it was so frustrating that I could not do it myself. I needed somebody behind me at all times, and in most cases; it was a nurse. I was in Spaulding for awhile before I went to my new school.

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