

Testimony for the Joint Budget Hearing Health/Medicaid 2/5/19

Sickle Cell Disease
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My Testimony 🌙❤ In living with SCD

Where do I begin. I guess you can say I was never supposed to be born but my mom couldn't see herself having the abortion her Doctors very much wanted her to have. At her second trimester of the pregnancy they started to notice something just wasn't right with me and the test they later ran just confused them even more. They couldn't even determine with certainty what my physical outcome would be. My Mom was in her early 20's when she decided to have me and not think about me possibly having some type of Down syndrome as they said she wouldn't be able to adequately care for my health expenses.

Pain has been a daily reminder of this Disease I live with. My earliest childhood memory is of being in the hospital in a tub full of ice to try and bring down a high fever. Caused by a drop in my hemoglobins level. I was about 5yrs old and I still remember her face the way she looked at me as if she had already lost me. She was so cold from holding me down in the tub. as the nurse kept checking to see if my fever had dipped. We were both cold and blue. After a few weeks in the hospital the virus I had subsided. Not much time passed before I got sick again with pain all over my body. some days my mom would have to pick me up from school and carry me home because the sickle cell pain crisis was to painful for me to walk home in.

This was a regular thing for me to miss school and for my mom to miss her other two children. Around Seven years old I began to have breathing problems especially at bedtime. It went on for weeks. Until they did a special scope test and saw my vocal cords covered in polyps which wasn't directly caused by sickle cell disease but having it sure made everything else worse. If it hadn't been my mother's persistence I would have lost my voice completely. Shortly after being diagnosed they started me on a blood transfusion every 3-4 months to make sure my blood levels are good enough. By age 13 I had 14 surgeries for polyps removal in my vocal cords, under my belt. Monthly check ups made sure the polyps weren't growing back. after that I had a pretty good two years of pretty much pain free.

Although when I almost turned 15 yrs old, I began what felt like the worst pain I had ever felt in my whole entire body! It felt as though someone had taken a bat and started batting practice in my limbs.

That crisis was a never ending crisis! It's also when I started getting my period which kind of became a monthly trigger for my pain episodes. My family tried everything to get ride of the pain from holistic, to acupuncture to you name it I've tried it. But all that was left was heavy opioids which my family has always been against because of all the the sick effects and not to mention the opioid dependence it creates. But my mom said she didn't know what else to try for my pain but the heavy pain meds. I started with Tylenol with codeine for breakthrough pain and slowly got use to that dose so they really quickly changed it to Dilouded, Oxycodone,

OxyContin, Oxymorphone, Morphine, Hydromorphone, Hydrocodone, Methadone, Fentanyl, and so many more. My Pain management Doctors really did try it all. So what worked best for me was Methadone 40mg Q8hrs. And then OxyContin and Fentanyl 12 hr patches. For that whole year I was a walking zombie until my body got use to the dose. My family was so scared biz I literally would wake up eat drink my meds and go back to bed then do it all again the next day. My family was so scared that I would overdose! That I was never left alone. One day I passed out at home my family just though I got drowsy but the truth was I had a silent stroke which later was confirmed with Ct scan. It was really weird to think I could've died but I have been told that I was going to die before I turned 5 yrs old. Then I was told I wouldn't live passed 10yrs old. But when I turned 20 yrs old I told myself I would try to enjoy my life as much as I could because I was gonna die soon so what was the point in taking care of myself if I was going to get sick anyways! By the time I was 17 yrs old I had my Gallbladder removed due to inflammation from Sickle cell disease complications. My disease has affected my education because I only made it to 11th grade. I tried home school, hospital school, tutoring but my problem was staying awake enough to do the class work. I really did try but my disease made it impossible. To much pain and not enough good days in a year. My mom had trouble keeping a job and actually finishing many careers because of me. Every time she was finishing a class I would get really sick and my mom cared more about me than any possible career which she never complained about it. But I always felt guilty for everything I prevented her from achieving. But she never complained not once! Our family hurt economically from my mom not being able to keep a job. It was tough and I never quite forgave myself. From a very young age I was put on SSI which my mom managed until I was 18 yrs old. But even with that extra income it wasn't enough. I mean think about it 500\$ a month doesn't even cover half the rent but I'm still great full.

When I was 18 yrs old I was so tired from all the transfusions, pain regiments and so many other invasive treatments that had failed that I told my mom I wanted to go to Dominican Republic for a vacation from my painful life. I didn't know it then but my doctors suggested to her that I don't even attempt getting on the plane because my body was too weak and my oxygen levels were not going withhold such a long airplane ride. But my mom said to them that I needed a break from all this and if that's the last thing my daughter does then at least she got to go to the beach and relax before my body gave up. I was very much in denial. I thought If I could just be normal for a few days in paradise (Dominican Republic) then it was worth every consequence. So there I was going on vacation with my best friend as a last goodbye trip which ended up lasting about 4 months and in the end I lived.

I didn't get sick as much over there my hemoglobin level went up and yes I still had pain but not as much as everyone thought.

When I came back to NYC I continued to get pain crisis, and a few other Sickle Cell related surgeries. But I was alive. I tried getting a job and I was so excited to have my first non family business related job.

I worked in a gym as a sales representative which I loved. But 3 months into the job I got Pneumonia which later turned into Acute chest syndrome. I was hospitalized for almost two

months and I lost my job. I was devastated because that was the only thing making me feel like a normal young adult. After that I fell back into hospitalizations which seemed to last months. The clinic I was going to for adult Sickle cell care was closing due to no funding in Montefiore Hospital and all the patients got a 2 week notice to find their next adult care clinic which back then there were not many. They sent me to a Hematologist and the care wasn't so great they kept trying to push medications which I didn't want to consume for my own personal reasons. The nurse who was assigned to me ended up becoming my fiancé with whom I'd have two healthy beautiful little girls named Angelica & Amanda De La Cruz.

My whole life I was told I would never be able to conceive. Which at one point I just thought I couldn't get pregnant. But as soon as we found out we were expecting, he got tested for the Sickle cell trait which he was negative for. Even then my Doctor at the time wanted me to have an abortion but I said no I was gonna have my child if it was the last thing I did! Fast forward 10 yrs I've had my ups n down but both pregnancies had little to no complications. They are healthy and that's all I cared about. I just wish I had more energy for them. But being a mom has definitely changed my life for the better I no longer want to give up. I just look at them and say to myself " they need you."

And honestly I always joke around but if it weren't for the strength they give me to fight for my life each day, I would have honestly given up already.

I still struggle but with the pic line in my arm I'm able to give myself ivy infusions which help me to hydrate myself every two nights.

And that's just my normal. I try my best to inspire others to never give up! "Things could always be worse."