

The long road to diagnosis, acceptance, and advocacy

Bitter journeys can have positive resolutions

A reminder that life is what you make it

By Berlange Presilus

I was born with Klippel Trenaunay Syndrome. Despite being born with a very rare syndrome, I am showing the world that beauty is attitude; it is beyond what the eyes can see. Born with a purpose to teach, my reality tells its own story. Hopefully it will empower others to dream out loud, own their truth and believe in the endless possibilities.

Growing up I felt ugly. I hated my leg; I hated being in pain all the time and unable to do what other kids were doing. My life has been a roller coaster of pain and emotions and I never felt good enough. I spent most of my teenage years in a dark place asking God “why me? What did I do to deserve this?”

I have been teased, laughed at and bullied for being different. My pain has always been bitter. I was always low on energy, had severe migraines, restlessness and paranoid. I would wake up from sleep with a cold leg due to insufficient blood circulation and numb curled toes from the subsequent

cramps. There were times where I would be taking a shower and I would feel a sharp stabbing pain and consequentially feel weak, only to realize that I had been bleeding without any apparent wounds.

I began to seek medical help nonstop but to no avail. The first doctor didn't know anything about my condition and there was nothing he could've done. The second, third, fourth... and onward were just as clueless as the first doctor. However, it was suggested to amputate my leg in order to eliminate the suffering caused by the pains and circulatory complications. Despite my medical situation, sleepless nights and restless days, I was able to hide my pain and stress, and find some relief through laughter and my own fashion sense.

My pain could be so utterly horrific that I preferred to hide most times. I felt so disconnected and I didn't know how to explain what I was going through to people. I never wanted momentary pity while the



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pain remained. Subsequently, this continued to feed into my depression.

In 2005 I made the choice to live a little, forget that I was “abnormal”, and believed that my right leg was not so unusual. However, that didn't last long. Two times in that year, I had a terrible blood clot, which led to me being rushed to the hospital. I was given some medication that only put me to sleep and I was kept at the hospital for further treatments. However, no helpful treatments were given beyond the sleeping medication, because the doctors didn't know anything about my syndrome or the cause of swellings. In that same year, an unbearable pain struck once again. It was extraordinary and uncontrollable. This time I thought that was it. My leg turned purple and my veins were popping. The following day, parts of my leg got very lumpy and my skin slowly began to soften. Two days later I had different open wounds with blood seeping through them. In the midst of all this, I never stopped praying. I prayed for my pain to go away, but it never did. So, I continued to seek medical help nonstop. Tired, helpless and suicidal, I decided to see one last doctor. I did not know what to expect, but the unexpected happened. The doctor

comfortably explained that this is a rare condition that impedes proper blood circulation. “You are not getting enough blood circulation to your heart which is a very bad sign.” He then went on about his disbelief of me having my menstrual cycle. With confidence, yet in deep regret, he finally broke the worst news to me... He said, “YOU WILL DIE BEFORE THE AGE OF 19”.

My world came crashing down. I became more depressed. Anxiety and insecurities had a greater effect on me in comparison to the actual physical pain. I battled with turbulent mood swings and self-consciousness. I became numb to my abilities. My pains and trials were completely unbearable. I stopped wrestling with my inner-self and caring about not feeling good. I stopped caring about life all together. However, I tried to always keep a smile in public, but slowly feeling dead on the inside while I continued to suffer from chronic pains.

At last, I met someone whom I like to call an angel...I met Dr. Garnette. He wasn't completely certain of what was ailing me, but confirmed signs of lymphedema. Subsequently, I did several surgeries and follow-up sclerotherapies to fix the veins. However, more superficial veins continued to form and my leg swellings became 10 times worse. It was recommended that I wear compression stockings to help with the swelling and to keep my veins under control. I continued to suffer over the years.

In 2011 I flew to Cuba. It was there and then I got diagnosed with Klippel Trenaunay Syndrome. Although I found out that there wasn't any cure for my condition, I further researched the syndrome and became empowered to nurture my abilities regardless of how strong or weak they are. I decided to own my truth boldly and live life with a grateful heart and full dedication, raising awareness and inspire the masses.

I grew up thinking that I was alone. I had no role model and no one to relate to. For that reason, I grew up confused, lonely, hopeless and unfitting. Once I recognized the strength and power within me, I made the decision to become the role



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model I needed while growing up, to others. I have created a platform called B-Revealed, aiming to reconcile one's views towards the stigma around different chronic illnesses and perceptions of beauty in society. To this day, there are times when I wake up with unbearable pain and ulcers draining with nasty fluid. I will feel sharp stabs in my heart and then my heart will skip a beat and continue to beat faster than normal. Other times, I will have to mentally drift to an unknown fantasy world just to escape my reality of pain. Nonetheless, I continue to put my best foot forward and remain optimistic...

Every day I put on my compression stockings and kick up my feet against the wall for at least 20 minutes and try to stay active, eat healthy and drink LOTS of water.

My mission is to show the world that despite being born with such a rare syndrome, beauty is introspective perception and one's attitude towards themselves and others. Beauty is not about outward appearances, but rather, the make up of one's character. Instead of chasing perfection and inspiring to be perfect, I became comfortable in being imperfectly PERFECT. While embracing my flaws, seeing beauty within myself, irrespective of society's perception and loving myself unconditionally. [LP](#)

Editor's Note:

Klippel-Trenaunay syndrome (KTS) is a rare disorder that is present at birth (congenital) involving malformation of blood and lymph vessels plus abnormal growth of soft and bone tissue. KTS occurs most frequently in the lower limb and is frequently associated with lymphedema.