

WHAT'S YOUR STORY

Tawny's Story



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As a kid I was very active, shocking I know! I played basketball and softball all the time, that is until the summer before my senior year of high school (1996). I starting having GI issues but, at that age, who wants to talk about having diarrhea! It got so bad that I wasn't eating anything but popsicles, I had a permanent tardy pass at school, and I had to kick people out of the bathroom at home! Eventually I was diagnosed with Ulcerative Colitis. I was also having gallbladder attacks at the same time. They did a scope and my gallbladder was so inflamed that they had to wait until it calmed down to remove it. Little did we know what else we would find out with that scope. We didn't know that our lives would change in a massive way with the next few words that would come out of the doctor's mouth. Oh but wait, my doctor didn't tell us this life changing news until he was in his car on his way home from the hospital. He called my mom and said "Your daughter has Primary Sclerosing Cholangitis (or PSC) but don't tell her, she doesn't need to worry about it. Have a good day." My mom went to the nurse's station and they were looking in medical books (nothing was electronic at that point) to find out what PSC was. They obviously told me I had PSC, but it never really phased me. I'm pretty lucky because I had no symptoms. Typically, it takes a really long time to diagnosis PSC.

From 1996-2002, my Ulcerative Colitis was the worst. They told me that I would need my large intestine/colon removed and I laughed at them and said, "I don't think so!" By 2002, I was begging them to take out my colon. In 2003, I had my tonsils taken out and if you ask my mom, she will tell you that was probably the worst surgery of them all. In 2007, my joints started swelling up, getting all red and hot and at times I wasn't able to move them. It made life pretty difficult. I was diagnosed with Palindromic Arthritis. My arthritis comes and goes when it wants and moves from joint to joint, from head to toe. The arthritis can be pretty debilitating during a flare up. We have this saying, "When my liver is good my arthritis is bad, but when the liver is bad the arthritis is good."

In 2009, I was looking for walks to participate in and I found PSC Partners. My mom and I went to the annual conference and it changed my life. Prior to this conference, I didn't realize that I was having PSC symptoms. I thought I had ants in my pants because I was constantly moving and itching all over my body (kind of like I had ants running all over me). After talking with others who understood PSC, I realized that I was itching because my liver function was declining.

In 2010, I was diagnosed with Primary Biliary Cholangitis (PBC), another liver disease. I didn't think anything of it, I was like "Oh well, not much I can do about it. I can't change it so why be mad." It was then that I started having more PSC symptoms and infections that caused me to be hospitalized many times. From that point on my body itched ALL over, but not just your normal itch, I felt like I was allergic to my blood. Severe fatigue caused me to sleep for days at a time. I had pain in my liver daily, nausea, fevers, night sweats, my skin and eyes started to become jaundice or yellow. I had so many infections that I couldn't get rid of that I went on long term rotating antibiotic. That lasted about 3-4 years.

In 2013, I had a bad flare up of my arthritis and started having other health concerns as well. I was diagnosed with Fibromyalgia. My eyes were terribly inflamed and I was at the eye doctor weekly. My fatigue got so bad that I was sleeping every minute I was not at work. I had to change jobs because of the decline. My memory was getting worse and more of a concern. I was diagnosed with chronic airway obstruction; my lung function was decreasing, causing me to be short of breath all the time. I couldn't have a conversation without being short of breath, which made it hard to run a meeting. My quality of life was really being effected. In 2014, I had to move back to my parents' home because of the decline in my health. I had to have a hysterectomy because of how my body was responding to everything with my liver. This is when our world changed, even more than we thought it had already; my liver was not bouncing back after my hysterectomy. My liver was at the cirrhosis stage, what is called end stage liver disease. Because of the cirrhosis, one of the worst and severest symptoms I had was Hepatic Encephalopathy (HE). My liver was not able to get rid of the toxins in my body, which affected my brain. This caused confusion, forgetfulness, slurred speech, poor concentration, personality changes, moodiness and I have a really hard time processing everything. I would sleep for 7 days straight and my parents would have to wake me up for meal and meds. New Year's Eve 2014 was a day that I will never forget. I went out to run some errands and I later realized that I was having an HE episode. I was driving around the parking lot at Walmart thinking I was supposed to be following my dad in his car, but my dad was at home and I was driving his car. I drove 2 blocks down from Walmart to the chiropractor and asked if my niece was there. They had just closed and they said to me "Tawny you guys were here earlier- your niece isn't here." I was confused and said maybe she is around the corner, but she wasn't. So, I went back to Walmart and spent 3 hours walking around. Every one of my family members called and asked where I was. The last call was from my sister and she asked what I was

doing. I said "I am looking for the olives, we need them for the appetizer." The olives were in the same place they had been for years. Tricia told me to come home and she would get them later. I started crying because we needed the olives but she convinced me to come home. I spent \$100 on nothing. As I was driving home I "came to" and realized that I probably need to stop driving. When I got home I spoke with my parents and sister and that was the last day I drove for a long time. But the HE didn't stop. I didn't understand how a server at a restaurant could take our orders, get our drinks and bring us food and I had been a server for years. I cried at church for no reason. When my body decided my day was done my mom would have to take me home from wherever we were and literally change my clothes and put me to bed like I was a little kid. I couldn't do anything. It was then my parents decided something needed to be done.

In March 2015, my parents requested a meeting with my doctor. As a result, it was recommended that I be evaluated for a liver transplant. But with PSC and PBC my labs were close to normal and my MELD score (the calculation they use to determine the severity of chronic liver disease) was very low. Because of my low MELD score my only option for a transplant was a living donor or I would die waiting for a deceased donor. Immediately, even before I was approved for transplant, my sister Tricia wanted to know when she could be evaluated as a living donor. July 3rd I was officially listed for transplant! Tricia called and set up an appointment for the living donor evaluation immediately! On August 26th, Tricia, my Mom, and Dad surprised me by coming home early. Tricia was wearing a shirt that said "Liver Available for Transplant". She was so excited she was crying and told me she was approved to be my living donor and we were scheduled for transplant on September 8th! I could hardly take it in. I am so grateful for the amazing gift of life Tricia gave me! Tricia's gift has allowed many new opportunities for my future, and I will always have a part of her with me. I am so blessed with the support of my family, friends, and fellow PSC family!

On 9/8/15 we had the transplant and I received 64% of my sister's liver! It was amazing. We were discharged after 7 days. I was readmitted with infections 5 different time and stayed in the hospital 39 of 56 days. I ended up having a biloma drain, a biliary drain, a chest tube (which I don't recommend!) and a PICC line so I could do antibiotics on my own at home. It was a rough 6 months and my family would agree! But I got through it, no, we all got through it!

Unfortunately, my liver transplant didn't cure my arthritis, fibromyalgia or chronic pain. I still deal with pretty severe pain on a daily basis and have to take several meds to help with my pain but they don't come close to taking it away. I have to adjust everything I do because of my pain. But again, I can't change it so why be mad about it. Don't get me wrong, it SUCKS and I hate it every single day, but why let it ruin my day and feel worse than I already do.

I am not able to work because of my arthritis, fibromyalgia, and chronic pain. But I also have to deal with the residual effects of the HE and the fact that it messed with my brain and I still have memory issues and other issues. I also have to take so many meds for my pain and for my transplant that those also mess with my brain. I get really confused at times, I don't understand the simplest things and I ask a ton of questions and it annoys people at times but sometimes I just don't get it. This also plays a role in the reason why I can't work. I may not be able to work but I volunteer as much as I can!!! I volunteer for University of Wisconsin Organ and Tissue Donation, Wisconsin Donor Network and Wisconsin Tissue Bank and for the Blood Center of Wisconsin. The days I get to volunteer I am so excited and happy that I am able to give back and encourage people to become organ donors and donate blood. I get to encourage people to help save a life - the lives of my friends and maybe even your family or friends. When I am not volunteering, I promote organ donation and drive a neon green car with Donate Life magnets on the side and a license plate that says SAVDME. I love stopping at a stop light and seeing someone read the magnets, it makes me smile, maybe they will decide that day to become an organ donor or even tell someone about this neon green car they saw. It starts a conversation.

I love my life! I am so grateful for the gift my sister gave me. I am so grateful for my family and my parents being by my side every single minute of every single day. I had PSC but PSC didn't and doesn't have me!