

## Justin's Story

On Friday, October 28, 2016, I went to a Halloween party. The next day, I was very hungover, but by Monday, I was still feeling very tired and sick. Nearly a week after the party, I told my brother how horrible I was still feeling, and that a headache had begun as well. I had to go to the doctor.

My regular doctor listened to my symptoms, ordered a blood test, and a CT scan. He brought me into his office the very next day to review all of my results. I don't remember what my hemoglobin level was, but I remember clearly when he said my CT scan was "glowing from head to toe." He then told me I was full of cancer. Much later, I learned that "glowing lymph nodes" can be due to many different factors.

At first, I was in total shock and afraid, thinking it was "game over". But, after I processed the whole thing, I felt a sense of calmness and believe it or not, my anxiety was low. At this point, I just wanted to get out and do everything! Now, I feel like maybe I was being very selfish. I was only thinking about everything I wanted to do versus thinking about how my family was probably feeling. I should have taken that time to spend with my family and my extended family. But, instead, I took off with a friend, lol! We went to a lot of music events, especially in Nashville, spending \$200+ a night. I was living like it was my last hurrah!

Eventually, I had a consultation with my hematologist. He reviewed the results of my blood work and said he didn't believe I had cancer! They tried to figure out what was going on, testing for everything from Lupus to Lyme disease, but I still wasn't feeling good. The doctors were taking my blood like crazy. Then they would say, yes, it is cancer, then no, it's not cancer, cancer, not cancer, cancer, not cancer. This went on for over 8 months.

Not able to work at this time. I finally thought about asking them for a referral to Mayo. It took nearly 7 months to get the referral, but then I couldn't get an appointment scheduled. I was calling every day. I finally called them and instead of pushing 2 for a NEW PATIENT, I pushed 1 for DOCTOR ( haha!), and it worked! I was finally able to talk to someone. I pleaded my case and had an appointment the following Monday.

But by the time I had the appointment at Mayo, my blood levels were improving. After two days of tests at Mayo, they mentioned wAIHA, but they couldn't diagnose me because their tests were not consistent with all my previous tests. They told me that if I had problems in the future, I should come straight back to Mayo.

Two years later, in March 2018, at my stepdaughter's birthday party, I had to show the kids how to do a flip off a big block at the trampoline park. I definitely showed them what NOT to do as I broke my leg and nearly ripped my ankle off! Not funny then, but funny now! But, soon after, as I was recovering, and would move from lying down to walking a short hallway to the bathroom, I would be out of breath, dizzy, and it felt like my heart was beating out of the back of my head. On a Saturday night, my wife said we should go to the hospital. I said no, that I was just out of shape. But when I woke up Sunday morning, I realized she had stayed up all night, worrying. She insisted we go to the ER. When I still refused, she told me she was afraid I could have a blood clot in my lungs. I jumped up and said, "Let's go!" Even with the broken leg, I was in a hurry.

## Justin's Story Continues—

After blood tests and X-rays, the ER nurse said, "You don't have a blood clot because you don't have enough blood!" They admitted me right away as my hemoglobin was at 5.8. They ordered a blood transfusion, but my body was rejecting it, so they had to do some kind of science to find a blood type my body would accept. It took until late Monday before I got the transfusion that my body didn't reject. Unfortunately, my hemoglobin only crept to 6. I was very tired, weak, pale, and very scared. I would wake up to make sure my wife was still there. She never left my side.

After a couple of days and a few more transfusions, my hemoglobin got up to an 8. I was able to go home for a day or two before going back to Mayo. The ER and my hematologist then put me on a very high dose of Prednisone. I hated the prednisone. I set an alarm for each dose. When my alarm would go off, my girls and I would all be like UGHHHHH! We all knew that for about the next 3 hours, I would have uncontrollable outbreaks of anger and rage. It was seriously like I turned into a different person. No matter how hard I tried to keep my head straight, I would still lose my mind for a bit. I don't remember how long I was on Prednisone, but it felt like forever.

Back to Mayo, they finally diagnosed me with wAIHA. Still on high doses of Prednisone, but preparing for Rituximab. But just before starting Rituximab, my hemoglobin got better and better. We decided to wait on the Rituximab and continued the Prednisone. Slowly, I got back to normal.

Thankfully, I have been in remission since 2019. I still have a lot of weird medical things that happen, though, like having chills and shivering so badly I can't get warm even with sweatshirts on and wrapped in blankets. I have had a couple of episodes where I completely panic and think I'm losing my mind. Sometimes my heart races, I lose my balance, and feel like I'll pass out. Once in the ER, they thought I was having a heart attack, so they did a Cardiac Enzyme Test and found increased enzymes, which can be a sign of a heart attack or heart damage. They did a heart catheterization, only to find no blockage.

I'm no doctor, but from what I know about Post-traumatic Stress Disorder (PTSD) and hypochondria, I have similar symptoms. If I see someone on TV get sick, I automatically think I'm sick, and if someone in my household gets a cold, I treat them like they have the plague (haha!).

COVID in 2020 was a nightmare. I was afraid of what it could do with wAIHA. I was afraid of the vaccine at first until the Warriors helped me understand that it wouldn't destroy my immune system. I got the vaccine, but only the first two or three shots.

I still have issues being in large crowds, but I push myself through it because some of the best parts of my life are live music, big events, and being around people.

**Disclaimer:** These patient experiences are personal stories and do not constitute medical advice. Please consult a qualified healthcare provider for medical guidance.

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