



William's Story

Markham, Ontario, Canada

In December 2022, shortly after recovering from the effects of my second COVID-19 vaccine, I noticed something wasn't right. I was extremely short of breath and initially thought I had caught COVID. But things didn't improve. I had zero appetite, I felt incredibly weak, and soon I began looking jaundiced. My urine was consistently dark, which alarmed me. Outside of the vaccine, the only major life change at the time was starting a new, high-stress job, but nothing else stood out. I just knew something wasn't right.

People around me began commenting that I looked "a bit yellow." It took about a week for me to realize I needed to go to the emergency room. I finally reached out to my family doctor, who told me to go straight to the ER.

At the hospital, they ran blood work and found my hemoglobin was dangerously low—somewhere in the 40s or 50s g/l (which is equivalent to about 4–5 g/dl in U.S. measurements). I felt confused and overwhelmed. I didn't know anything about autoimmune diseases. It was a lot to take in, especially when they started me on prednisone right away, which had extremely negative effects on me from the start.

While I was in the ER, I was fortunate to be seen by Dr. Henry Solow, a hematologist. He ran Coombs tests and did additional blood work. After ruling out any underlying cancers through CT and MRI scans, he confirmed that I had warm Autoimmune Hemolytic Anemia (wAIHA). I saw him again for a formal hematology appointment within about a week of my ER visit, which helped me start understanding what I was up against.

My treatment journey has been far from easy. I started with prednisone, which I took for about 1.5 years. It caused uncontrolled weight gain, made it hard to sleep, and really took a toll on my physical and emotional health. Early on, I needed a blood transfusion to temporarily boost my hemoglobin. After prednisone, we tried Rituximab, but unfortunately, it had very little effect on me. Thankfully, I didn't have issues accessing care or getting treatments—just the usual insurance paperwork back and forth during the process.

After a relapse, we moved on to CellCept, which I stayed on for about a year. While it brought me into a state of compensated hemolysis, it also made me feel tired all the time. Still, it helped stabilize things.

Looking back, so much about this disease has surprised me. At first, the diagnosis didn't make any sense, and I was shocked by how limited our treatment options really are. Even now, there's still a lot we don't know about wAIHA, and that's both frustrating and motivating.

Like many others with wAIHA, I experienced stress, anxiety, and other mental health challenges. I was already feeling the pressure from COVID and my new job, but the emotional impact really hit after I was diagnosed. The uncertainty was overwhelming.

Today, I'm grateful to say that I'm in compensated hemolysis. My energy is great, and I'm even able to do high-intensity training at the gym. My hemoglobin levels still fluctuate, but overall, my daily life has improved significantly.



What's helped me cope the most is doing my own research and attending the wAIHA Warriors Annual Meeting. Hearing from others who are living through this has been incredibly empowering. It helps to know you're not the only one going through it. I also have a great doctor who takes the time to explain what's going on in my body, which has made a big difference.

I truly believe that exercise and eating well played a big role in my recovery. Reaching compensated hemolysis without being on any immunosuppressant drugs requires a strong body, and building that takes work. Even if you're tired, some level of movement and physical effort will help you over time.

To anyone newly diagnosed or still trying to find their way: you are not alone. We, as wAIHA Warriors, will always support one another. Take your time, listen to your body, and keep pushing to find the treatment that works for you. Most importantly, work on strengthening your body, even in small ways. Healing takes time—but it is possible.

Meet William:

William grew up in the Greater Toronto Area and never moved. He finds life in the Greater Toronto Area quiet and calm, so not as exciting as other big cities he's visited in his travels.

William enjoys The Expanse TV show because he considers himself a sci-fi geek. Staying true to being an engineer by profession, and to be curious about how others perceive technology will evolve, lifts his imagination.

William enjoys traveling to Europe and Asia. He recently found that China is a pretty fun place to visit with all of their technological advancements. However, he finds a certain charm in Europe's unique culture that he hadn't experienced since he is Chinese.

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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