Sean's wAIHA Story

I was 44 years old when my symptoms first appeared in early May of 2019. It started on a Monday—I remember it clearly. I felt an unusual level of fatigue and shortness of breath while exercising. I figured it might be a passing flu. But even after a full night's rest, the fatigue only worsened instead of getting better. Over the next few weeks, I lost the ability to exercise altogether. Something just wasn't right.

After three weeks of feeling exhausted, short of breath, and unable to function normally, I made an appointment with my primary care provider. Unfortunately, she wasn't available, so I saw the physician's assistant instead. I described my symptoms and even suggested, "I think I might be anemic." I explained that I was feeling pain in my legs—like they were being starved of oxygen—when I tried to run.

She dismissed my concern, saying she heard a heart murmur and suspected a heart condition. She ordered a stress test, but I insisted she also order bloodwork. The stress test came back inconclusive. The blood work showed a hemoglobin of 8, but still, no one could explain what was going on. I was confused and, honestly, scared. My health was declining rapidly, and I still had no answers.

On Monday, June 10, 2019, things reached a breaking point. I felt exceptionally weak. My resting pulse was nearly 100, and I was breathing rapidly even while sitting still. I went to the emergency room. My fever was 103.5°F, and my hemoglobin had dropped to 5.1. I was admitted immediately. They ordered CT scans, X-rays, more blood work, and called in gastroenterology, infectious disease, and hematology.

That first night, I saw both the GI and ID teams—neither had answers. I had to spend the night in the ER waiting for a bed. The next morning, a hematologist walked in and said, "I think I know what this is." She ordered a Coombs test, which would take three days to come back, but she didn't wait to begin treatment. She started me on intravenous prednisone and gave me a blood transfusion. That afternoon, I was finally moved to a hospital room upstairs.

The following week was a frustrating cycle: every morning, my hemoglobin would be around 6.0. I'd get IV prednisone, and by noon, it would rise to 7.5. But by evening, it would fall back down to 6.0, and I'd need another transfusion. This loop went on for a week. Finally, the medical team started me on Rituxan. After a full 8-hour infusion, my hemoglobin finally stabilized. I was discharged two days later with a hemoglobin of 10, after 12 days in the hospital. I completed three more Rituxan infusions over the next three weeks as an outpatient.

I've been exceptionally fortunate. Since that initial treatment in 2019, I've remained in remission. My energy isn't quite what it used to be, but that might just be age catching up with me—I'm over 50 now. Still, I can do anything I want, and I'm back to living a normal life.

What surprised me most was that this was happening to *me*. I had done everything right—exercised, eaten well, gone for regular checkups. It seemed unreal that I could be diagnosed with such a rare condition. Honestly, I think that disbelief is part of what delayed me from seeking care sooner.

I also want to recognize how critical my support system was during that time. I was living alone in a city far from family, but as soon as I was diagnosed, my friends swung into action. I rarely had a night alone in the hospital. They made sure I had everything I needed. My mom came down from Virginia, and my sister flew in on the day I was discharged. And my now-husband was there every step of the way. I couldn't have asked for a better team of support.

I didn't face any issues with insurance, financial barriers, or finding a hematologist, which I realize is a privilege not everyone has. But I did struggle emotionally in the aftermath. This disease came out of nowhere, and it could come back just as suddenly. I dealt with intense anxiety, especially in the early months. Every new symptom made me hypervigilant, worried it was wAIHA returning. With time and distance from the active stage of the disease, I've been able to relax and breathe again.

When I was first diagnosed, I had never even heard of wAIHA. There were no support groups, no reliable sources of information—nothing. Helping to co-found *wAIHA Warriors* has been the greatest coping mechanism I could have asked for. For me, it matters for three big reasons:

- I've helped create the organization I wish had existed when I was diagnosed.
- It's incredibly normalizing to be around others who just *get it*—no long explanations needed.
- And most importantly, it's deeply rewarding to talk to newly diagnosed patients. I can help them feel less alone, give them a safe space to ask questions, and share the kind of insight that only someone living with this rare disease can offer.

To anyone reading this who's just starting their journey: You've got this. The hardest part—not knowing what was wrong—is behind you now. Ask your doctor every single question, no matter how small it may seem. And remember:

You are not wAIHA. You are a person living with wAIHA.