



## **JaNelle's wAIHA Story**

*Colby, KS*

In the summer of 2020, I began to notice changes in my body that I couldn't quite explain. I was suddenly, and overwhelmingly, fatigued—more than just the usual tiredness you can brush off. Walking up a flight of stairs left me breathless, and I started having heart palpitations that seemed to come out of nowhere. This all happened shortly after my first case of the pandemic illness, so at first, I assumed my body just needed extra time to recover.

My husband noticed the change, too. He'd comment that I seemed more worn out than usual, but together we chalked it up to getting older. Neither of us imagined it was something serious. When the palpitations persisted, my doctor ordered a Holter monitor to check my heart rhythm. When that came back negative, I expected the mystery would soon be resolved—but it didn't.

My local physician decided to order lab work, and when all the results came back as “abnormal,” I was stunned. I even wondered if the lab had mixed up my chart with another patient's—how could I feel so unwell if my labs were fine? Sensing something was still off, my doctor dug deeper. She ordered another round of tests—CBC, Coombs, CMP, and several others I can't even remember now. She also consulted a hematologist for guidance.

The hematologist requested additional testing, including a 24-hour urine cortisol and a full battery of labs. When my hemoglobin level came back at 8.4, the reality of the situation began to sink in. For someone who had never been seriously ill, the number alone was terrifying. When the Coombs test came back positive, everything started moving quickly. I saw the hematologist within a week, and—unlike many others with wAIHA—I received my diagnosis very quickly, within about a month of my initial symptoms.

Hearing the words “warm autoimmune hemolytic anemia” for the first time was surreal. I felt a rush of fear and uncertainty. What did this mean for my future? Would I get better? Would life ever feel normal again?

My treatment started with Rituxan—two rounds of infusions. They made me incredibly tired, but unfortunately, they didn't stop the hemolysis. My doctor was clear and direct with me, which I appreciated. Next came folic acid (which I'm still on), prednisone, and CellCept. I stayed on prednisone for about two to two and a half years. The side effects were exactly what you'd expect: irritability, energy spikes, and appetite changes. While prednisone helped in the moment, I was relieved when I was finally able to taper off. CellCept became my long-term treatment plan, and I've now been on it for three years. Thankfully, I haven't experienced significant side effects from CellCept or folic acid.

Those first two years were tough. Fatigue forced me to realign my social life and daily activities. Simple things—like running errands or attending a gathering—took more energy than I had. But my husband was unwavering. On the days I couldn't keep up, he picked up the slack without complaint. My family, too, surrounded me with support, and my church community and prayer life became a vital source of strength. Faith played a huge role in helping me manage the emotional weight of living with a rare autoimmune disease.

By doing my own research, I learned as much as I could about wAIHA. Connecting with online communities like wAIHA Warriors was a turning point—I found people who understood what I was going through, who could answer questions or simply listen on the hard days. That knowledge and community gave me a sense of control and hope.

Now, more than four years later, I'm in compensated remission thanks to CellCept, and my labs are stable. I feel like I'm living my life much as I did before my diagnosis. I can do all the things I want to do, though I've learned to pace myself. It took a full two years to feel like myself again, but the last two-plus years have been so much better than the first.

If you're newly diagnosed, I want you to know this: the initial fear and uncertainty will subside. You'll learn a new "normal," and it won't always feel this overwhelming. Lean on your support systems—family, friends, faith, and online communities. Engage, ask questions, and educate yourself, but don't accept wAIHA as the end of your life. It's not. There is life—and joy—after diagnosis. Celebrate the small victories and the good days, and give yourself grace on the harder ones. You are stronger than you think, and even in the most uncertain moments, there is hope.

### **Meet JaNelle:**

JaNelle grew up in Michigan, and her favorite place to vacation is Estes Park in Colorado.

Instead of a favorite book, movie, or TV show, JaNelle is a self-proclaimed "news junkie."

JaNelle and J.W. recently celebrated their 50th wedding anniversary. When asked about their children, JaNelle says, We are blessed with three daughters, two of whom are Army wives. One son-in-law retired a year ago, and they moved back close to us. Our other son-in-law will retire on October 1, 2026, and they also plan to move back near us. Our middle daughter is a Nurse Practitioner and such a blessing to us! And, we have five precious grandchildren, ages 19, 15, 14, 14, and 10.

In addition to their children and grandchildren, JaNelle and J.W. share custody of a Doodle named Woody with their granddaughter. He's 17 pounds but behaves like a big toddler.

Interestingly, JaNelle and J.W. are both firstborn children in their respective families. However, there are differences: JaNelle is Type A, while J.W. is Type B. JaNelle is right-handed, and J.W. is left-handed. You should see them fold a sheet!

**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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