



Monaco's Story- Sydney's Journey with wAIHA: A Mother's Perspective

I first noticed something was wrong with Sydney in October 2021, after she had the flu and a stomach bug. At first, I thought she just needed extra time to recover. But one morning, she woke up jaundiced—her skin and eyes were so yellow that I knew immediately this was serious. We rushed her straight to the emergency room, marking the beginning of a journey I could never have imagined.

In the ER, doctors ran bloodwork, including a CBC and CMP. Hearing that her hemoglobin was critically low, around 6, filled me with fear and confusion. I didn't understand exactly what was happening, but I knew it was serious. As a parent, watching your child so sick and feeling powerless is terrifying.

Sydney's diagnosis of wAIHA did not come quickly. Her first episode in October 2021 focused on stabilizing her symptoms. She had another episode in May 2024, but even then, the cause wasn't clear. It wasn't until her third and most serious episode in January 2025 that doctors were finally able to confirm wAIHA through testing. Her hemoglobin was again critically low, and the positive Coombs test finally gave us clarity. The process was long, frustrating, and emotionally exhausting. As her carepartner, I felt fear for her health, but also relief in having a name for what we were facing so we could move forward with a treatment plan.

Sydney has undergone multiple blood transfusions during her episodes. Each transfusion helped stabilize her in the short term, but it was stressful knowing transfusions weren't a long-term solution. She has also been on prednisone, which helped control her hemolysis but caused mood swings, fatigue, and changes in appetite. Watching her cope with these side effects while trying to live her life as a young adult has been incredibly difficult.

Adding to the complexity, Sydney was later diagnosed with another ultrarare disorder—one that doesn't yet have a name—that causes her small blood vessels to form blood clots. This condition can trigger liver and kidney failure during each episode, compounding the risk and uncertainty of her health.

Emotionally, this journey has been overwhelming. Each relapse brings deep anxiety, not only because of the unpredictability of wAIHA, but also because of the life-threatening complications of her second disorder. Work, school, and family life have all had to adapt to treatments, appointments, and recovery periods. The financial strain of repeated hospitalizations, specialist travel, and ongoing medications has added stress on top of the emotional weight of caregiving.

Despite the challenges, we focus on what helps us cope. Leaning on faith, family, and close friends has been essential. Practical support, like meals or simply checking in, has made an enormous difference. Connecting with others who understand rare diseases, through advocacy groups or online communities, has provided comfort and strength.

Right now, Sydney is stable, but each day requires vigilance. Her energy and daily life fluctuate depending on how her body is coping. We celebrate stretches of stability, but remain aware that another episode could bring serious complications. We've learned to take things one day at a time, finding joy in small moments and gratitude for the good days.

To anyone living with wAIHA, or loving someone who does: you are not alone. This journey can feel isolating, confusing, and overwhelming, but there is a community of people who understand. Trust your instincts, ask questions, and don't be afraid to advocate for yourself or your loved one. Celebrate the stable labs, the good days, and the moments of laughter. Lean on your support system, and give yourself grace on the harder days.

Most importantly, remember that you are stronger than you think. Even in the middle of fear or uncertainty, there is always hope and a community ready to walk this road with you.