Let's Talk!

Profile: Whitney Ward

By Trudie Mitschang

next day, I spiked a fever of 105 degrees Fahrenheit. I was taken to Children's Hospital where it was discovered I had septic arthritis. That was easily treated, but my doctors also discovered my blood counts were not where they were supposed to be. I was tested for many diseases, but nothing came back positive, so my doctors gave me the very broad diagnosis of autoimmune hemolytic anemia, complicated by combined immune deficiencies.

Trudie: What was your initial treatment plan?

Whitney: My care was trial and error at best because my doctors didn't know what they were dealing with, but thankfully they did everything right to keep me stable. In 2010, my immunologist let me know he sent my case to the National Institutes of Health (NIH) because there was a new disease that had just been discovered to which I had a lot of similarities. A few months later, I had my first visit at NIH. I didn't have the suspected disease, but my team was so intrigued by my symptoms, they created a protocol for unknown diagnosis. In time, it was learned my disease was caused by a rare gene mutation that occurred at some point in my mother's womb, and I was the first person in the world to be discovered with it. My NIH team and a doctoral student worked on my medical case for three years, yet they couldn't find any patients who shared my diagnosis. In time, it was learned my disease was caused by a rare gene mutation that occurred at some point in my mother's womb, and I was the first person in the world to be discovered with it. My NIH team and a doctoral student worked on my medical case for three years, yet they couldn't find any patients who shared my diagnosis. My team surmised that most babies were either stillborn or miscarried, so it was a miracle I survived.

Trudie: Is it true you got to name your disease?

Whitney: Because I was a creative writer, my NIH team asked me to help choose a name. I chose MAGIS syndrome. MAGIS fit the scientific protocol, but it also held a special meaning. MAGIS means “more” in Latin and also references the Latin phrase “to the greater glory of God.” Today, there are 21 known cases of MAGIS syndrome, and 19 of us are living.

Trudie: When did you develop an interest in writing and journalism?

Whitney: From the moment I could read and write, it was my outlet to cope with my chronic illness. Reading offered me an escape from my reality. When I read books, I could be the heroine of the story who saved the kingdom from destruction. Or, I was the best friend of the main character in the book, and I went on the adventures with her. When I read a book and lost myself in the story, I was no longer the sick girl who missed out on so many special things, and my heart needed that. Whereas reading was my way to escape my reality, writing was a way to vent about my reality. I can’t tell you how many journals I have from my childhood and teen years in which I vent about how I was treated and the many memories I had to miss out on because of my chronic illness. This showed me I enjoyed writing, and I seemed to have a talent for it. That was very exciting for me because much like an avid sports fan or athlete critiques the plays or decisions of the game they are watching or playing, I did that with the books I read. I often thought, “I would have had the character do y instead of z,” or “I wish the book would have ended this way.” And as an author, I have the power to make those decisions. Of course, there

AS A REGULAR contributor to IG Living, Whitney Ward may seem like a familiar face. But, what you might not know is how she went from being a rare disease patient, barely getting by on public assistance and part-time salaries, to fulfilling her goal of becoming a published author. Her journey primarily revolved around clarifying income caps for those on disability within her home state of Ohio. Her hope is that her lessons learned can inspire others to push back against external limitations to pursue their dreams.

Trudie: Let’s start with your health history. How were you diagnosed with chronic illness?

Whitney: When I was born, I had many congenital defects, and as I grew up, I developed asthma, battled sinus and ear infections, and suffered from multiple bouts of pneumonia. At 6 years old, I woke up one morning with swollen, hot and red knees. I couldn’t walk for hours, and when I finally could walk, it was with a severe limp. The
is probably someone out there reading my books giving them the same kind of critique I used to give the books I was reading. LOL.

**Trudie:** Tell us about your path to becoming a published author and the hurdles presented by disability income limits.

**Whitney:** It took several years after I graduated from college to find a path. In 2013, I tried to work as a part-time student aid at a local elementary school, but I came uncomfortably close to my salary cap, so I had to quit my job. In 2015, I asked a case worker at the Department of Job and Family Services how much income I could earn if I returned to the workforce, and I was given false information. It was so enraging! My fear was that I would publish a book and the income received would cause me to lose my Social Security Income (SSI) benefits.

**Trudie:** How did you push for answers?

**Whitney:** After a lot of legwork, the local commissioner I contacted connected me with a U.S. representative. Congressman Brad Wenstrup has helped me the most; his office pointed me to federal-based solutions. I learned what I could do with my benefits, about different programs available to me, as well as the pros and cons of each one. The most important piece of information I received was my personal salary cap that was calculated based on the type of benefits I received. This was the total salary I could receive a month and still receive my SSI check and Medicaid benefits. The best news was that there is a federal program called the 1619(b) plan for people who receive disability benefits. With this plan, if a recipient begins making more than his or her threshold allows, then the individual can be placed in the 1619(b) plan in which he or she would no longer receive an SSI paycheck, but would continue to receive Medicaid as long as he or she remains within the state’s appointed threshold.

**Trudie:** Getting those answers required a lot of perseverance.

**Whitney:** It did, and each step led to the next. I started by reaching out to my local officials (a good place for anyone to start). Their help and advocacy led me to state officials, who eventually pointed me toward federal-based solutions. Patients need to find out what their breakeven is for federal and state benefits. The Social Security Administration has a document titled *The Red Book — A Guide to Work Incentives.* It’s complicated, but it contains the answers patients need whether they want to start a business, go back into the workforce or become a published author like me.

**Trudie:** Tell us about your book proposals.

**Whitney:** I submitted proposals in the summer of 2020, and by the fall of 2020, I had signed a book contract with a publishing company and a contract with a literary agent. In the fall of 2021, my first book was published. It is a picture book called *MORE Than Your Mountains* for children with disabilities to understand that their disease doesn’t define them and God has a plan for them. Since then, I have published four books, and I’m currently working on my fifth. The path was exhausting, and many times I felt like I had bruises and cuts from the battle I was fighting, but I am so glad I didn’t quit because I wouldn’t be where I am today.

**Trudie:** What lessons did you learn while advocating for yourself?

**Whitney:** While waiting and in times of feeling as if I would always be stuck with no direction, I still did what I could to be ready if opportunity arose. I went to writing conferences, I networked with other authors, I entered writing contests so professionals in the industry could see my work and I cultivated connections with publishers, editors and agents in the industry so they would know who I was when I pursued my dream of becoming an author. And that benefitted me greatly because when the time came to accept those long-awaited contracts, I was prepared.

**Trudie:** What advice do you have for those who want to look into their own income limits?

**Whitney:** The key to getting the answers you need is tenacity. It can be difficult because there are going to be times when you feel like you’re getting absolutely nowhere, and it can feel easy to give up because it’s exhausting managing a chronic illness and fighting to pursue your civic rights. But you must be tenacious and remember that lawmakers hear hundreds of thousands of issues and concerns from their constituents each year, probably even more, and they can’t keep up with every person they hear from. So, tenacity is key here. Keep pursuing these offices until you receive the answers you need to feel confident about going back to work and pursuing your dreams while keeping your disability benefits secure.

**Editor’s note:** For those who want assistance in finding their Continued Medicaid Eligibility status, visit [www.ssa.gov/disabilityresearch](http://www.ssa.gov/disabilityresearch). For help contacting local, state and federal officials about your specific situation, reach out to Whitney Ward at Writergirl0801@gmail.com.

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