



Profile: Whitney Ward

By Trudie Mitschang

WEIGHING JUST 4 pounds 9 ounces at birth, Whitney Ward battled an endless array of health problems and endured multiple hospital visits as an infant and child, but doctors had no clue what was making her so sick. Then, following a series of “divine” appointments, Whitney was invited to be the subject of a dissertation at the National Institutes of Health (NIH). That invitation led her to become the first person diagnosed with what is now known as MAGIS syndrome — a name she came up with and submitted to NIH for consideration. Today, the busy college graduate is an aspiring writer who hopes her story will inspire others to live fully in spite of chronic illness.

Trudie: Your symptoms began at birth. Tell us about that.

Whitney: When I was born, I looked like a premie who was 10 weeks early, even though I was full term. I had clubfeet and dislocated hips, and when I was just a few months old, I battled chronic ear infections and severe asthma. I was prescribed medication that helped, but not always. Sometimes, my



Whitney Ward spent years living with a disease no one could diagnose until an immunology PhD and medical student discovered its gene mutation. She is now one of four people living with MAGIS syndrome, named by Whitney herself.

asthma attacks got so bad, the only thing my parents knew to do was stick my head in the freezer. Or, if it was winter, they would take me outside to try to get my lungs to relax. As time passed, I also battled viral pneumonia and chronic ear and sinus infections. No one knew what was wrong, and doctors predicted I'd outgrow it.

Trudie: Your health took a turn around 6 years old. What happened?

Whitney: One Saturday morning, I awoke with excruciating pain in my knees. They were red, hot and swollen. The least touch or movement caused me to scream out in pain. The next day, I spiked a fever of 105 degrees Fahrenheit, and my pediatrician made arrangements for my parents to take me

to Cincinnati Children's Hospital the following Monday morning. I was diagnosed with septic arthritis, which was easily treated, but this discovery led to the understanding there was much more going on. My blood counts were all over the place.

Trudie: What led to your diagnosis of septic arthritis?

Whitney: I underwent a lot of testing and learned I had a form of autoimmune hemolytic anemia, which basically meant they had absolutely no clue what was wrong. My medical care was sporadic at best but eventually led me to Nationwide Children's Hospital when I was 11 years old, where I have been a patient for 19 years. I gained a wonderful team of doctors that consists of my hematologist, immunologist and rheumatologist. Eventually, they were able to tell me I had combined immune deficiency complicated by autoimmune hemolytic anemia.

Trudie: What was life like prior to diagnosis?

Whitney: It's funny, I was actually an athletic, rumble-tumble tomboy. I was quick, sturdy and strong. I have no doubt if I had been completely healthy, I would have become a college athlete. But because of my illness, I felt like I stood on the sidelines watching the lives of kids my age keep going while mine just stopped.

Trudie: Was it tough making friends?

Whitney: Growing up was a little lonely. When your illness is invisible, not everyone understands or believes what you're going through. I felt all



people could see were my deformities. One thing my disease causes is excessive warts, and one time in junior high, a boy in my class told me I should be in the *Guinness Book of World Records* for having the most warts. The pain and humiliation I felt in that moment was almost more than I could bear.

Trudie: How did you stay strong?

Whitney: There were three things God gave me that helped me get through the heartache. The first was my family. My parents were always there to support and advocate for me, my sister was my best friend and cheerleader, and my grandparents were always there to lend a listening ear. The second was my church family. The third was my love for reading, which allowed me to escape and forget about all of the uncertainty.

Trudie: When did you become involved with NIH?

Whitney: I was a 22-year-old college sophomore, and my immunologist casually mentioned he sent my case to NIH. He said there was a new disease that had just been discovered called DOCK8, and I had similarities to it. He hoped I would fit the protocol. I was repeatedly cautioned it was unlikely the research team would figure out what was wrong with me, but right from the start, I knew I was about to embark on an unforgettable and remarkable journey.

Trudie: How did you end up naming your own disease?

Whitney: I met Ian Lamborn three years after becoming involved with NIH. He was an immunology doctor of philosophy and medical student from the University of Pennsylvania who came to NIH to work on his dissertation, and he was given my case. He is actually the one who discovered the new gene mutation that caused my disease. I was the first person in the world discov-

ered with this gene mutation, and I used to joke about having the disease named after me. They explained that when it came to naming a disease, the rules had changed. No longer did the disease consist of a person's name, but the name needed to form an acronym that stood for the prominent symptoms of the disease. In the end, I came up with five names, and my favorite was MAGIS syndrome. It fit the scientific requirements; plus, MAGIS means more in Latin and is related to a Latin phrase: "To the greater glory of God." To me, this was absolutely perfect because I wanted other patients to know they are more than their disease.

Trudie: When did you learn your name was selected?

Whitney: I attended Ian's dissertation with my family, and at the end, he came over and presented me with a hug and bouquet of flowers and announced to my complete and utter amazement they had selected MAGIS syndrome! In that instant, I received closure I never had before. The years of pain, scary medical procedures, 26 surgeries, missed opportunities and a lonely childhood had not been in vain, but it had been for a greater purpose.

Trudie: What's your treatment plan today?

Whitney: It's been a long journey and lots of trial and error, but today, I take rituximab every six months and am treated with subcutaneous immune globulin.

Trudie: How has being involved with the Immune Deficiency Foundation (IDF) impacted your life?

Whitney: I have only been involved with IDF for two years, and the first thing I did was participate in one of their primary immunodeficiency awareness walks. I discovered there were peo-

ple out there like me who completely understood what I was going through. I gained a community of friends I never knew existed.

Trudie: What is your day-to-day life like now?

Whitney: I am actually the healthiest I have ever been. Everyone who knows me realizes this is a complete and total miracle. In December 2011, I almost died; my hemoglobin levels dropped to 2.8, and from all appearances, the disease I had fought all my life was about to take my life. But miracle after miracle happened, and my health turned around so much quicker than my doctors ever imagined. I have never looked back. I have been on six mission trips, I'm a Sunday school teacher at my church, I'm active at my local gym, I help my grandpa harvest a garden, I volunteer for IDF, I am the founder and president of Peculiar Treasures (an online book club), and I now have many dear and special friends who are my prayer warriors. When I look back at where I was in 2011 to where I'm at now, I can see how God gave me beauty from ashes.

Trudie: What are your goals?

Whitney: I want to be married and have children. I have been asked what I would do if I passed on my gene mutation to my children, and I believe I would raise them the way I was raised and instill in them they are more than their disease. Careerwise, I am working hard to launch my writing career. I have a bachelor's degree in creative writing with a minor in journalism. And, I write a weekly blog titled "More Than My Mountains," which can be found at morethanmy mountains.blogspot.com. ■

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