



Profile: Jessica Schexnayder

By Trudie Mitschang

JESSICA SCHEXNAYDER is an author and South Louisiana native living with neurologic and autoimmune disease. She is the GBS/CIDP Foundation International patient point of contact for Baton Rouge, La., and surrounding areas.

Trudie: When did your health challenges begin?

Jessica: In 2010, I began to have odd symptoms with seemingly no connection to each other. I had digestive issues, I was fatigued, my hands cramped when I typed or wrote, I had a feeling of pins and needles in my legs. It was a strange compilation that didn't make sense. Initially, I attributed it to my busy lifestyle. I was a wife, mother, full-time employee and part-time student. But, as my symptoms progressed, I began to seek the advice of multiple specialists, none of whom had answers. My doctor merry-go-round continued for two years until I was referred to a neurologist, Dr. Amer Awad. He listened to me, believed me and started the workup to figure out the puzzle.

Trudie: What led to your diagnosis?

Jessica: After undergoing a spinal



Jessica Schexnayder had a long journey to multiple diagnoses, including neurologic diseases affecting both her central and peripheral nervous systems (transverse myelitis and CIDP), as well as CVID.

tap, it was determined I had chronic inflammatory demyelinating polyneuropathy (CIDP) and I needed intravenous immune globulin (IVIG) as treatment. We began the insurance approval process for home infusion, but on Sept. 19, 2012, I was admitted to the hospital for an attack that paralyzed me from the waist down. Tests revealed I had both central and peripheral nervous system disease. Dr. Awad immediately started me on IVIG and high-dose steroids, which reversed the paralysis. I now have an umbrella diagnosis of demyelinating disease under which I have subdiagnoses of transverse myelitis (affecting the central nervous system) and CIDP variant multifocal motor neuropathy (affecting the peripheral nervous system).

Trudie: What other issues did the IVIG treatment uncover?

Jessica: The revelation of my immune deficiency was due to me being placed on IVIG for my nervous system disease. Since birth, I've had chronic ear, sinus and respiratory infections. Doctors rotated me from one antibiotic to the next trying to keep infections at bay. I've had three sets of ear tubes, mastoiditis, too many bouts of sinusitis and bronchitis and two cases of severe pneumonia. It was thought that I was just "sickly" from being born prematurely, or that I had allergies. The dots were never connected. However, the IVIG infusions created a noticeable difference nearly stopping the infections. It was concluded I had an undiagnosed immune deficiency, possibly common variable immune deficiency (CVID), prior to IVIG therapy.

Trudie: What is your current treatment plan?

Jessica: Currently I'm on biweekly IVIG infusions plus medications to help control pain and muscle spasms. In the beginning, IVIG alone wasn't enough to control my symptoms, and I continued to decline, at which point my neurologist added Solu-Medrol (steroids) to my infusion regimen. While the steroids helped, the side effects were so drastic I had to stop taking them. In 2015, my neurologist added rituximab, a monoclonal antibody, to my treatment plan. I received eight infusions over a two-year period, which stabilized my decline. No two



patients are alike, and treatment plans differ for each. IVIG and rituximab is the combination that works for me.

Trudie: How do you keep your illnesses from defining who you are?

Jessica: That's a really hard question because a part of me is defined by my illness. At first, the complexity of my situation was so much in the forefront, I was truly overwhelmed. It took a long time to make peace with the fact that I will always have this in my life, and I could either let it overrule me or I could turn it around and use my experience for the benefit of others. In 2016, I began a mission to help patients like myself and joined the GBS/CIDP Foundation as a volunteer. I'm now the patient point of contact for Baton Rouge, La., and surrounding areas.

Trudie: Tell us about your work as an author.

Jessica: My book *Fragile Grounds: Louisiana's Endangered Cemeteries*, co-authored with Mary Manhein, was released in September 2017. It highlights a research project in which we documented 138 threatened cemeteries in Louisiana that will eventually be lost to the Gulf of Mexico through forces such as coastal erosion, storm surge and sea level rise. I've always been fascinated by cemeteries and how communities are culturally connected to these sites. Conducting this research and writing this book with Mary has allowed me to delve into my passions: anthropology, history and the geography of coastal Louisiana.

Trudie: What motivates you and keeps you positive?

Jessica: My two best motivators are my husband, John, and my son, Cameron. They encourage me daily, and I am so very grateful for both of

them. My faith also guides me. I believe that God put me on this path for a reason, and I try to remember that whether I'm in the valley or on top of the hill.

Trudie: What has been your biggest struggle, and how did you overcome it?

Jessica: My biggest struggle was having to medically retire from my job at age 40 and to resign from the degree I was working toward. I was not ready to submit to either one of those realities. It took those first few months at home to realize I could not have sustained that pace in the long run. In retrospect, I was able to overcome these struggles by reaching out and befriending other patients in similar situations, which led me to volunteering in patient advocacy, a humbling and rewarding experience.

Trudie: What advice do you have for others with chronic illness?

Jessica: My advice is when it comes to your health, you are your own best advocate. Create a folder with your diagnosis, test results and a current list of your medications, and take it with you to your appointments. If the doctor needs the information, you already have it in hand. Also, most important, listen to your body and rest when needed.

Trudie: What have you learned about yourself?

Jessica: I've learned I'm stronger than I previously believed and even though I have chronic illnesses and disability, I still have a lot to offer.

Trudie: What are your goals for the future?

Jessica: I plan on continuing my volunteer work with the GBS/CIDP Foundation and promoting my book and research. In May, I participated in the Grifols Patient Community Open



Today, Jessica uses her experiences as a volunteer point of contact in Louisiana for the GBS/CIDP Foundation International.

House in Los Angeles, Calif., where I was able to experience the entire process from plasma donation to the creation of lifesaving medications, including IVIG. While there, I was able to meet several people while they were donating plasma. It was a humbling moment; I was able to say thank you and tell each of them that their selfless gift was giving me a better quality of life. One fact I learned is that it takes approximately 465 plasma donors to treat one CIDP patient (like me) for one year. That's astounding! I'm thankful for my experience at Grifols because it opened my eyes to the impossibly large number of donors needed for the creation of these medications. I hope to take what I've learned and use it to encourage the public to help fill this need. I'm not sure where else the path will take me, but I'm looking forward to the journey. ■

TRUDIE MITSCHANG is a contributing writer for *IG Living* magazine.