



*Jamie Stewart, who suffers from multiple illnesses and nearly lost his life, is learning to live in the moment, and is a volunteer and advocate for rare diseases.*

**JAMIE STEWART** is a former *IG Living* blogger and chronic inflammatory demyelinating polyneuropathy (CIDP) patient who has faced numerous health setbacks over the years, including a failed stem cell transplant. Following the loss of his marriage and subsequent battle with depression, Jamie has learned to appreciate his own resilience and hopes to help other patients to do the same.

## PROFILE: Jamie Stewart

By Trudie Mitschang

**Trudie:** Tell us about your first diagnosis.

**Jamie:** In November 2010, I received the H1N1 [influenza] vaccine. Shortly thereafter, I experienced severe nerve pain in my thighs and slowly started losing muscle strength. Symptoms continued to degrade, and approximately 18 months later, I was officially diagnosed with atypical CIDP. I initially tried high-dose prednisone with no luck. I was then treated with intravenous immune globulin (IVIG), but the dosing levels were incorrect. As I continued to get sicker, I sought a stem cell transplant to hopefully stop the disease progression. My goal was simple: stop the disease, keep my job and restore my quality of life. I was accepted by three highly accredited international stem cell transplant centers and chose Moscow, Russia, because that center had the most experience with this type of procedure.

**Trudie:** What was it like to undergo a stem cell transplant?

**Jamie:** The transplant itself was pretty much insignificant. I had a few minor issues, but all were quickly resolved by the medical staff. Upon returning home, I was to wait six months and have a lumbar puncture to determine if the stem cell transplant was a success.

Unfortunately, my inflammatory markers did not improve, and the transplant was a failure. I knew going in that this was a possibility. Data show that stem cell transplantation is about 80 percent successful for multiple sclerosis, but data was not available for CIDP patients, as it was too new.

**Trudie:** When you first blogged for us, you were married. Tell us how your illness affected your relationship with your wife.

**Jamie:** Chronic illness is hard on a marriage, very hard. Roles change within the marriage. Things get taken for granted, communication breaks down and, eventually, walls get built up. It didn't help that neither of our families took an active role in assisting us as we went through this. I don't think people can fully understand the stress that comes with a rare disease. Not only were we trying to understand what was happening to my body, but we were constantly having to fight with doctors, insurance companies and the supposed friends who thought I was faking.

There are only a few places a person can turn to for help. I live in a small community, and there are no advocacy programs available, at least none for CIDP. I did reach out to national

organizations, but none had advocates in my area. *IG Living* was the only organization that truly assisted.

My ex and I had talked numerous times about how the stress was affecting each of us. I was aware that I needed to talk with a mental health provider, someone I could go to blow off steam when I felt overwhelmed. I encouraged her to do the same. No one tells you what to expect when dealing with CIDP. We didn't know that at times my skin would be so sensitive that taking a shower would be painful. No one told us that with the increased pain and fatigue, intimacy would become an issue. Patience and understanding were eroded as we communicated less and less.

**Trudie:** What happened when you returned from Moscow?

**Jamie:** I knew before I left for Moscow that things were not good in our marriage. By this time, I alternated between barely being able to work and being bedridden. My ex had become so depressed that she wouldn't leave the house except to go to work. I did implore her to see a counselor, but she refused. The last straw was the day she called me a burden.

**Trudie:** Your health took a turn for the worst shortly after your marriage ended. What happened?

**Jamie:** I kept having horrible bouts of fatigue accompanied with upper-respiratory issues. I knew that I was IgA- and IgM-deficient; I was told this can happen after receiving chemotherapy. I also knew I was under immense stress with the divorce and everything else in my life. When it felt like my blood was stopping, I knew I needed to see a doctor. After a few tests, I learned that I have secondary adrenal insufficiency, low testosterone and probable common variable immunodeficiency. It

was a good thing I got tested. My cortisol levels were so low that I had become disoriented. I was on the verge of a full-blown adrenal crisis, which can result in death. It was not a great way to begin your newly single life.

**Trudie:** What is your current medication/treatment plan?

**Jamie:** I am on many medications: IVIG 40 grams every other week, daily testosterone gel, hydrocortisone replacement, narcotic pain medications, pregabalin, tizanidine, Ambien and a statin for high cholesterol. I will probably need to add an antibiotic to keep the upper-respiratory issues under control. I use a steroid inhaler and have an oxygen concentrator for when I sleep. Even with all these setbacks, the plan is to improve my quality of life. My goal is simple: to be able to enjoy life to the fullest. I want to travel more often. I still volunteer and am an advocate for rare diseases.

**Trudie:** What lessons have you learned from all of this?

**Jamie:** I have learned that I am my best advocate. Doctors can be challenged, and when a doctor is unwilling to work with you, then it's time to fire the doctor and find a new one. Don't waste your time and energy on trying to change a doctor's

mind. Also, a rare, chronic illness is unbelievably stressful. I would suggest anyone diagnosed seek out a mental health professional. Mental health is so important, but is rarely discussed. The circle of support will be small, if any. I had to

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learn that if I had cancer, I would have received a tremendous amount of support and help, but when people don't understand what you have, they really don't know how to engage.

**Trudie:** How do you stay positive in the face of so many challenges?

**Jamie:** Living in the moment has really helped me to stay grounded. I realize that things will usually get better, no matter the circumstance. This realization came after my adrenal crisis. I take enjoyment in the things that I lost the ability to do, but have regained — like taking my dogs for walks. I allow myself to have “pity parties,” but they can only last one day. If after one day I am still feeling down, I seek out my mental health doctor. New hobbies have also helped me to feel good about myself again. I am learning to draw and paint, both very poorly, but it is fun! ■

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