Let’s Talk!

By Trudie Mitschang

Constance McNamara Romanowski was anemic her entire life, but it wasn’t until 2005 that she was diagnosed with Evans syndrome (ES). Today, she is the executive director of the Evans Syndrome Community Network, which helps people with ES to connect.

Constance McNamara Romanowski lives with multiple chronic illnesses, most notably the rare and debilitating Evans syndrome (ES). Her journey has been a difficult one, but today Constance is the executive director of the Evans Syndrome Community Network, whose mission it is to provide a safe networking haven for individuals whose lives have been impacted by ES. Her story inspired us.

Trudie: What was it like growing up with chronic illness?

Constance: At the age of 2, I had a violent reaction to penicillin. This was at the very beginning of my personal experiences with weakened immunity and autoimmune problems. From that point on, I was chronically anemic. When I started menstruating at age 11, my flow would be so heavy that I would pass out. Every time my blood work came back showing that I was anemic, the doctors would just explain it away, saying I “wasn’t eating well.” Later in life, the doctors said it was because I was in my childbearing years, and later they said it was because I was in perimenopause. Unfortunately, no tests were ever performed to determine the underlying cause.

Trudie: How were you diagnosed with ES?

Constance: In April of 2005, I got very sick. Years before, I was diagnosed with irritable bowel syndrome, and this seemed like a really acute attack. I ended up at the urgent care clinic, where I was diagnosed with stomach flu and prescribed an antibiotic. A week later when I returned to work, I noticed very tiny red dots appearing on the insides of my wrists. They didn’t itch, weren’t raised and were all uniform in size. I saw my doctor and she sent me to the emergency room for a CBC and chest X-ray. As I waited to be seen, the red dots spread to my feet and up my legs.

Trudie: What happened next?

Constance: It turned out the red dots were called petechiae, which are actually tiny hemorrhages just under the skin, the result of a low platelet count. A normal count would be 100,000 or higher; mine had fallen to about 4,000. And my hemoglobin, which should be at least 11.5, was 8. They did a battery of tests, including a bone marrow biopsy, ruling out all other diseases before they told me that I had Evans syndrome.

Constance: ES is a combination of idiopathic autoimmune hemolytic anemia and idiopathic thrombocytopenic purpura. Those two things together are ES. In layman’s terms, this means that the immune system has turned against itself, and the wrong cells are being marked for destruction. The immune system is in overdrive, marking healthy red blood cells and platelets for destruction by the spleen.

Trudie: What are the symptoms?

Constance: Symptoms vary, but things to look for include dark urine; an enlarged or painful spleen; fatigue; pale skin; a rapid heartbeat; shortness of breath; yellowing of the skin and/or whites of the eyes; abnormally low blood pressure; excessive or easy bruising; clusters of tiny red or purple dots on the skin; prolonged bleeding from skin injury; bleeding from the gums and nose; blood in the urine and/or stool; and unusually heavy menstruation. The crazy thing is that a person can have ES and have absolutely no symptoms at all.
Trudie: How is ES treated?
Constance: Prednisone tops the list. Sometimes anti-rejection drugs are used to treat the problem like a rejected organ. Sometimes doctors turn to an IV treatment called rituximab, which is a chimeric monoclonal antibody that was first used in the treatment of lymphoma. Once all other medical interventions are exhausted, a final option may be a bone marrow transplant.

Trudie: What was your experience with intravenous immune globulin (IVIG)?
Constance: For me, IVIG was the stop-gap that saved my life while waiting for IV steroids to kick in. I don’t think most people realize that when they give blood or plasma, there are many things that can be done with that donation. IVIG is one of those things. It’s mind-boggling to think how many people had to donate blood in order for me to get just one bottle of IVIG — it’s likely thousands, and I’m very thankful.

Trudie: Are you still on IVIG?
Constance: No, but there may come a time when I need it.

Trudie: What is the Evans Syndrome Community Network and what motivated you to start it?
Constance: When I was first diagnosed, I went straight to the Internet in search of information. The problem was there was not much available. But, I realized that I wasn’t in this alone; ES strikes roughly one in one million people, so there had to be others out there. I needed to find a way to get from this desperate, hand-wringing stage to a place where I felt more empowered.

My husband and I started a website and began gathering information that we thought might be helpful. We called it the Evans Syndrome Community Network. Our hope was that we could reach others all over the world who shared this diagnosis.

Trudie: How did you get the word out?
Constance: Through a fluke. I joined Facebook, and I started a group there as well to benefit those impacted by ES. The group grew slowly at first, and then it started to pick up. Now, we have almost 400 members from all over the world, and they’re quite talkative. We’re going through the process of creating a full-fledged nonprofit foundation for our group. Our website is shutting down and going through a refit, but our Facebook page is up and running. We also are working with the National Organization of Rare Disorders (NORD) in their effort called RareConnect, a new social network where rare disease patients can connect with others globally.

For more information about Evans Syndrome, visit: www.rareconnect.org/community/evans-syndrome and www.evanssyndrome.net.

Trudie: What are your goals and dreams?
Constance: My ultimate goal in life is just to make a positive difference in the lives of those around me. This helped guide us when we came up with the motto for the Evans Syndrome Community Network: “Together, we will make a difference, standing shoulder to shoulder.”

Trudie: What advice would you offer others?
Constance: Be persistent if you think something is wrong. Don’t let anybody tell you it’s in your head or you’re being silly. Be your own best advocate. Try to live each day to the fullest. Every moment is a blessing. And, remember: You can make a difference. Just try it and see.

TRUDIE MITSCHANG is a staff writer for IG Living magazine.

If your life depends on immune globulin and you have a unique experience to share, we want to feature you in this column! Email us at editor@IGLiving.com.