**Let’s Talk!**

**Profile: Tammy Keddy**

By Trudie Mitschang

Tammy Keddy is a certified nurse who was diagnosed with common variable immune deficiency (CVID) when she was 38 years old. Despite the challenges, Tammy has a positive outlook on life and even videos her treatments to share with other patients on her YouTube channel.

**Trudie:** When did you first experience CVID symptoms?

**Tammy:** I grew up with chronic ear infections, sinus infections and gastrointestinal problems. I was always in the doctor’s office and on antibiotics. As I grew up, I missed a lot of school, and later as an adult when my infections progressed to severe respiratory illnesses, my work attendance suffered greatly. I felt like I was letting my patients down.

**Trudie:** Tell us about your health crisis that led to a diagnosis.

**Tammy:** In 2019, my health significantly worsened. I started the year with pneumonia and was nasally intubated in the intensive care unit (ICU). It was a long, difficult recovery, and once I felt better, I ended up back in the hospital with atrial fibrillation. My pulse rose to over 200 beats per minute, and all medication attempts to lower it and put it back in a regular rhythm were unsuccessful. They put the paddles on my chest and started administering a sedative, but before it could take effect, they had to shock me twice in a procedure called cardioversion. I was in the cardiac ICU for a week before going home.

**Trudie:** How did you finally find out you had CVID?

**Tammy:** The next week, I ended up being taken to the emergency room by ambulance because I could not breathe; it felt like my lungs were full of cotton. I learned they were full of clots. Yet more bad news, but this time things were different. I was being treated as a whole person as opposed to different parts of my body being treated separately — and the person responsible for this was named Dr. Jason An who solved a 38-year-old puzzle. He tested me for everything, and the pieces finally clicked into place. I was low in all aspects of my immune system, especially my immunoglobulin (IgG) levels. He told me I tested positive for CVID.

**Trudie:** How much did you know about CVID prior to diagnosis?

**Tammy:** I remember reading about primary immunodeficiency disorders and immunocompromised patients in school, but mostly in the context of AIDS/HIV-related illnesses. I had never heard of CVID specifically until I was diagnosed.

**Trudie:** Tell us about your adjustments to intravenous immune globulin (IVIG).

**Tammy:** It took a year or so to get the right dose and frequency, but since starting, I have had only a few episodes of major infections with hospitalizations. It is night and day in terms of how I feel on a regular basis. It did come a bit too late for a few health issues though. I now have permanent damage in the form of recurrent pericarditis, chronic kidney stones and a clotting disorder that requires daily blood thinner injections, as well as an injection that stops the pericarditis from recurring so frequently. I also gained a lot of weight from the steroids, most of which I have now lost since I only take them in a medical crisis situation. The worst side effects of all of this are the lost jobs and opportunities when I do get sick and am hospitalized. It doesn’t matter how good you are at your job: If you can’t be there, you don’t get to stay.

**Trudie:** What is your treatment plan today?

**Tammy:** My treatment plan is always changing. I just lowered the dose and frequency of my IVIG infusions. For the past two years, I was infused with 85 grams of IVIG two days in a row every three weeks. After I lost the weight I gained from the steroid treatments, it was lowered to 60 grams every four weeks; however, we learned that the dose wasn’t enough because I started getting ear and sinus infections again and my levels dropped to being subtherapeutic. We are slowly increasing the number of grams again until the infections go away and my IgG levels increase.

**Trudie:** How has your life changed since the pandemic hit?
Tammy: I spent 20 years working in a hospital, in mental health and addiction settings. I earned my certification in addiction medicine and spent a year working as an outreach nurse in an outpatient setting. When the pandemic hit, I changed careers to work from home performing online COVID-19 testing for those who were traveling and required testing by their employers or those who had been exposed to the virus. I took a huge pay cut to work at a job that would not expose my weakened immune system to COVID-19. I spent almost two years living with my mom so I would not be alone during that time. She has been my rock during all of my illnesses and hospitalizations.

Trudie: What lifestyle adjustments have you made?

Tammy: I have learned how to be kind and gracious to myself, which was hard to do because I felt like I was letting everyone I knew down. I would make plans and not go because I didn’t feel well, and after canceling plans a bunch of times, I would stop being asked. I’ve also learned how important hydration is! If I don’t drink enough water, I get sick more easily and have side effects from the treatments. I also don’t label any food as “bad” like I used to. When I lost over a hundred pounds after stopping the steroids, I agreed that I could eat anything I wanted, just in smaller portions. If I do overeat, I forgive myself and just plan better for the next meal. I also force myself to attend events. I love getting dressed up and putting on makeup, and once I am out socializing, I feel great; it is just getting out that is hard. One thing I’ve learned is not to plan anything the day after my infusions. I allow myself to sleep and binge-watch TV shows. It helps me to recover.

Trudie: Tell us about your patient advocacy work.

Tammy: I have documented my journey with CVID on YouTube under TammyKeddyVlogs. I record my treatments, my hospital stays and post fun things as well, including my amazing holidays down South! Even if only a few people learn about CVID by watching my channel, I feel like I have accomplished something.

Trudie: Are you part of any patient or support groups?

Tammy: I do read through some CVID Facebook groups, but I find that the support I receive from my mom, doctors and specialty nurses is more therapeutic. Now that COVID-19 is not as prevalent, I will look for a local group with people my age to attend.

Trudie: What do you wish family and friends understood about CVID?

Tammy: I wish people knew that I am sorry I canceled again, that I didn’t call them back or tell them I am sick and in the hospital again. It gets old, and I get that. I also wish people understood that I still wear a mask not to get attention, but because isolation and fear of other people is natural for someone with a weakened immune system. And I am scared. I am scared to be around anyone who coughs or has a cold because catching pneumonia for me could mean days and days in the ICU and possibly not getting better. I really wish people understood that taking supplements and exercising aren’t going to fix me, and that I give more Christmas gifts to my healthcare team than I do to friends and family!

Trudie: What are you thankful for?

Tammy: I am grateful for the few friends who have stuck it out with me and who support me by just being there. I have also learned that no matter how old you are, your mom will always be your number one supporter and best friend. Thanks mom!

Trudie: What has living with chronic illness taught you about yourself?

Tammy: To be my best advocate and to let family members know what my medical wishes are should I become incapacitated. I have had to have some serious talks with my medical team when I have felt I wasn’t being given the best care. They are hard conversations, but necessary.

Trudie: What advice do you have for others?

Tammy: Trust your gut. When you think anything is wrong or feels different with your body, get checked. I have been told so many times that if I didn’t get medical attention when I did, I would not have made it.