Profile: Jessica Goddard

By Trudie Mitschang

AT 17, JESSICA Goddard is an outspoken and active high school honor student who teaches dance and serves as a primary immune deficiency (PI) disease advocate in her spare time. Although she's lived with common variable immune deficiency (CVID) her entire life, this fearless young woman has never let chronic illness define her or limit her goals.

Sick her entire life and diagnosed with CVID at age 13, Jessica Goddard has nevertheless excelled in school and dance and has ambitions to become a clinical pharmacist or immunologist.

Trudie: When were you diagnosed with CVID?

Jessica: I was diagnosed with CVID at the age of 13. Before I tell you how I came to be diagnosed with CVID, it is worth noting the average years between onset of symptoms and diagnosis is nine years. This is not necessarily due to misdiagnosis, but because CVID sometimes takes a while to present itself. Thanks to my doctors, I was diagnosed and began antibody treatment much earlier than the average age of diagnosis.

Trudie: What were your symptoms?

Jessica: The first physical signs of having an immune system defect arose at the age of 2 when several large lymph nodes were identified in my neck. After ruling out possible causes such as mononucleosis and other infections, it was decided to remove the largest node when I was 4. I was diagnosed with immune thrombocytopenia (ITP) before the surgery because my platelets were at 12 microliters (normal is 150 to 400 microliters). From age 4 to age 10, I took a combination of high-dose steroids and a continued low-maintenance dose to stabilize my platelet counts. During that same time, I was treated with antibiotics for 23 diagnosed ear or sinus infections. I had tubes put in my ears at age 8. I also had chronic sinusitis at the same time.

Trudie: Were you initially misdiagnosed?

Jessica: My immunologist first tested me for CVID at age 6 with the vaccine challenge that involves testing four weeks after getting the pneumococcal, DTP (diphtheria, tetanus and pertussis) and HIB (Haemophilus influenzae type B) vaccines. Tests revealed I had protective titers to all of the vaccines but almost no titers to the pneumococcal vaccine, and my immunoglobulin (IgG) levels were continuing to decline, but couldn't conclude if they were artificially reduced by the steroids. Six months later, after suspending steroid use, I was retested for the pneumococcal vaccine response and IgG levels, and the pneumococcal titers had an improved response and my IgG levels increased. At that time, CVID couldn't be conclusively diagnosed.

Trudie: What finally led to a diagnosis?

Jessica: I continued to take steroids until age 10 to maintain adequate platelets, but due to concerns over long-term steroid use, I was treated with three doses of Rituxan. For the next two years, my ITP was in remission, and I had limited ear infections. But, then, at age 12, I proceeded to have ear and sinus infections almost every month. I returned to my immunologist to investigate further, and testing indicated a very low IgG level and almost non-existent IgA level, as well as undetectable vaccine titers. CVID was then the official diagnosis.

Trudie: What was your initial treatment plan?

Jessica: I was started on intravenous immune globulin (IVIG) infusions once a month in the hospital for the next 18 months. After starting infusions, the occurrence of ear and sinus infections dramatically declined.

Trudie: When and why did you

switch from IVIG to subcutaneous IG (SCIG)?

Jessica: I transitioned when I was 14 to SCIG. I have been treated with SCIG at home for the past two and a half years. I started high school during my second year of IVIG at the hospital, and I had to miss a whole day of school each month. I experienced scarring in my veins from the frequent IVs (plus blood draws). I did not want to have to get a port to prevent future vein scarring. It was hard to make up the work and miss the lectures in the classroom. Additionally, I hadn't yet told many people about my diagnosis, so I had to make excuses or avoid the questions from kids at school about why I was out of school again and why I had bruises on my arms. It is much more comfortable and flexible to do my infusions at home and on my own time.

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Trudie: What do you wish people understood about your illness?

Jessica: Chronic fatigue has a large impact on my daily life and makes it hard to focus in school. I need 10-plus hours of sleep every night to feel awake. Also, I work very hard to get the grades I do considering the impact fatigue has on my life. I'm in the top 12 percent of my class and will graduate with honors in STEM, National Honors Society and a score of 1400 on my SAT.

Trudie: Where does dance fit into your life?

Jessica: I have been dancing for 14 years, eight competitively. Until this past year, I have danced ballet (pointe), jazz, hip hop and lyrical; however, this year, I will continue pointe and tap. I am also a teaching assistant with one of the younger ballet classes. I cannot entirely keep my illness from interfering with dancing, but I do my best to work around it. I always inform my dance teachers of days I will be missing and why, and they understand I may not be able to come to class because I am not feeling well.

Trudie: What are your goals for the future?

Jessica: I want to go to school to become either a clinical pharmacist specializing in immunology or an immunologist. I also want to continue with PI advocacy work.

Trudie: What type of advocacy do you do?

Jessica: Participating in Immune Deficiency Foundation Advocacy Day really opened my eyes, especially on legislative issues that may impact those dealing with a rare and chronic disease. I am a plasma awareness coordinator and visit a few local plasma donation centers. Plasma cannot be manufactured in a lab, so thanking the donors for their lifesaving donations is very important. My favorite volunteer role is being a member of the Teen Council where I attend Teen Escapes and other events and help mentor youth living with chronic illness.

Jessica volunteers for the Immune Deficiency Foundation as a plasma awareness coordinator to thank donors and on the Teen Council where she mentors youth living with chronic illness.

Trudie: What advice do you have for other teens living with chronic illness?

Jessica: Don't force yourself to tell anyone about your disease until you are comfortable, including nonimmediate family members. Take control of your health, and stand up for yourself when you are in an uncomfortable situation. Do your infusions on your own time; don't feel pressured to stick yourself or set up your infusions until you are ready. My parents still help me with my infusions, and I know other people who do the same. It's OK to ask for help and support.

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