



Despite being ill since a child and diagnosed with multiple diseases, including common variable immune deficiency, Chelsey Safken feels incredibly blessed to have a loving husband, Joe, and three healthy children: Lilia, Trace and Alana.

CHELSEY SAFKEN was just shy of her 16th birthday, when she was diagnosed with osteosarcoma (bone cancer). Since then, this resilient young wife and mother of three children aged 5 years and younger has battled multiple setbacks and illnesses, including a diagnosis of common variable immune deficiency (CVID). While many might feel discouraged by such a deluge of health challenges, Chelsey's positive attitude and strength have helped her overcome adversity and live life to the fullest — no matter what.

PROFILE: Chelsey Safken

By Trudie Mitschang

Trudie: Tell us about your diagnosis and health history.

Chelsey: I was diagnosed with CVID 15 years ago, and with hereditary angioedema (HAE), a rare inherited blood disorder, five years ago. Like many who have complications from CVID, I have a history of cancer, hemolytic-uremic syndrome, numerous surgeries and so many infections that even if I tried, I would never be able to remember them all. With HAE, I sometimes have extreme flares that seem to go through cycles, while other times, I can go for months without any swelling episodes.

Trudie: When did you begin being treated with intravenous immune globulin (IVIG)?

Chelsey: I started IVIG infusions when I was 12 years old. Because I was young, I chose the denial route for a lot of years. I wanted to be able to keep up and do everything that a typical healthy person is able to do. Around age 18, I decided that I wanted to take a break from my IVIG infusions; I was doing well, so I thought maybe I didn't need them anymore. I have a wise doctor who let me take a break so I could see for myself how much it was helping me. He explained to my mother that no one can make someone do infusions — they must want to — and he was right. After completing my sophomore year of college,

I became so sick that I begged to start the infusions again.

Trudie: What considerations did you have when starting a family?

Chelsey: Because of the type of chemotherapy I received when I was young, my oncologist told me that if I wanted to start a family, I had to have all my kids before I turned 30. That was hard because it didn't give me a lot of time to decide what I should do. My husband and I love kids and always wanted to have a large family, but there was a huge concern about passing on my immune deficiency to our children. We were still debating about what to do when we got the unexpected news that I was pregnant. It was a very difficult pregnancy (it was during the pregnancy when I was diagnosed with HAE). My son Trace, who is now 5 years old, was born on our three-year wedding anniversary. My daughter Alana is 3-and-a-half years old, and my youngest daughter Lilia is 22 months old. I feel very blessed because, so far, all of my children are incredibly healthy. My children are the greatest blessing I have in my life. If I had to do it over again, I would still have them because I honestly can't imagine life without them.

Trudie: Where do you have your infusions?

Chelsey: For about 10 years, I



received my infusions at an infusion center. When I had my son, I switched to home care. I absolutely love having my infusions at home, and my nurse has become part of the family. I receive Cinryze infusions for HAE twice a week, and my IVIG infusions every two weeks.

Trudie: Have you had any challenges with insurance coverage?

Chelsey: I think the hardest part of dealing with insurance companies is when I have to switch policies. Sometimes trying to get authorization takes time and, on occasion, I've had to miss infusions while waiting for approval. No matter what, I always know within the first couple weeks of January, I will hit my out-of-pocket maximum for the year. Knowing medical bills are a major part of our budget, my husband and I always have to factor that into our expenses. Thankfully, there have been some amazing programs that have helped cover some of the medical expenses, which I am so grateful for.

Trudie: How does chronic illness impact your marriage?

Chelsey: Sometimes my husband has to take on extra responsibilities around the house and with the kids due to my health. He's usually really good about it, because he knows if I rest, I typically rebound a lot quicker. I've never been one to sit on the sidelines, so it's really hard for me to rest. He is always the one telling me I need to take it easy and not push myself too hard. My kids are now starting to ask a lot more questions about why I always have to go to the doctor. I try to answer them openly and honestly because I don't want them to be afraid, but I also shield them because they are young.

Trudie: Do you belong to any support groups?

Chelsey: I don't belong to a support group, but I have an incredibly supportive family. I have a large extended family and am really close to my parents and siblings. They are always there for me, and I lean on them a lot.

how to set boundaries for myself that help me to stay well.

Trudie: What frustrates you most?

Chelsey: I think people really misunderstand what a genetic immune deficiency is. Most people have only heard of

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Trudie: Do you have a diet or exercise regimen to manage your health?

Chelsey: I don't follow an exact exercise routine, but I am incredibly active. I love to go for walks and hikes with my family. I feel staying physically active is incredibly important to staying healthy. It helps boost my mood and body. As far as diet goes, I try to eat only fresh foods and avoid any processed foods. I eat a large variety of fresh fruits and vegetables, especially those that I know have anti-inflammatory properties.

Trudie: You're a regular contributor for the IMMUNOe blog. How did that come about?

Chelsey: I started writing because IMMUNOe approached me. They wanted to have a blog from a patient's perspective, and I began writing it to help others.

Trudie: What's been the most difficult part of living with chronic illness?

Chelsey: I spent a lot of years living with a real fear that if I admitted being sick, illness would define me. I now realize that my disease isn't who I am, but it's definitely a part of me. I've now learned

acquired immune deficiency, and they are very different things. I also wish people understood it's not a laziness issue or an excuse when I need rest. It's a real condition, and just because I look totally normal doesn't mean that I am. I feel like it's a blessing and a curse because with these diseases, I usually look completely healthy.

Trudie: What has living with illness taught you?

Chelsey: I don't want my life to be limited by the things I missed out on or by my health conditions. I have learned the importance of maintaining a healthy body both physically and emotionally; wellness is the whole person. Even though having rare diseases brings a lot of complications with everyday life, it has also taught me a lot of good things. The most important lessons I've learned are that every moment is precious and life needs to be lived to the fullest! ■

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