



Ric Dolore, who was diagnosed with CVID and psoriatic arthritis after years of illness, still doesn't receive treatment due to the high cost. Yet, despite frequent illness, his goals are to raise awareness about immune deficiency diseases and, one day, be able to pursue his career goals.

IN 1993, Ric Dolore was blessed with his first instrument: a Fender Squier Stratocaster. With a small Fender practice amp and guitar lessons from a great jazz guitarist named Pace Connor, Ric opened his soul to music. After playing in cover bands throughout his youth, Ric made it his goal to pursue a career in music production. That is, until a diagnosis of common variable immune deficiency (CVID) at age 35 put those dreams on hold.

PROFILE: Ric Dolore

By Trudie Mitschang

Trudie: Tell us about your journey to a diagnosis.

Ric: I was misdiagnosed several times with everything from scabies to athlete's foot. During that time, I had strep throat four times in five months. My fevers were so severe that I sweated through an entire mattress and memory foam. At one point, I was admitted to the hospital and misdiagnosed with lupus. In the end, it took 11 doctors and four years to find out I had CVID. At the time, I still had the diagnosis of lupus and was dealing with a rampant skin infection. I was prescribed steroids and steroid creams, which only made things worse. Eventually, I was referred to a rheumatologist who reviewed my health history and suggested I quit work and "live in a bubble."

Trudie: How did you respond to that advice?

Ric: It's very hard to make a living working from home. It's possible, but it's very hard. You have to do quite a bit to be able to work from home; you need a quiet place to work, office furniture, a computer and Internet. It wasn't really an option for me.

Trudie: How did you keep your music career going at that time?

Ric: At the time, I was pursuing a career as a music producer. When I became ill, I had to cancel my collaborations and DJ events, but I was not willing to give up, and I did not want being sick to keep me from pursuing my goals. I ended up launching a crowdfunding campaign to raise enough money to make music and work from home. I was hoping I could avoid being exposed to germs, and since music is a stress reliever for me, I was hopeful it would benefit my health as well.

Trudie: Were you successful?

Ric: Unfortunately, I was not able to raise enough money. I'm currently working full time as a trainer for a call center, but pursuing music on the side. I would love to finish the song I'm working on and release it. Any profit above costs would be donated to the Jeffrey Modell Foundation.

Trudie: Tell us about your other diagnoses.

Ric: When my immune system went wonky, the remaining parts became hyperactive, which is when I was diagnosed with psoriatic arthritis. I also developed allergies for things I've eaten and lived with my whole life: coffee, dairy, chocolate, cats, dogs — it's been a struggle. To put some perspective on it,



I'm actually a master barista and have worked in coffee shops my whole life. I'll never be able to do that again.

Trudie: What is your treatment plan?

Ric: I do not have a treatment plan at this time due to the out-of-pocket medical costs. I simply cannot afford it. I have not had an immune globulin infusion since September 2015. As a result, I've been sick for months with ear infections that may have caused permanent damage to my right ear, along with so many other illnesses along the way.

Trudie: Do you have health insurance?

Ric: I do have insurance, but I have not been to the immunologist due to the cost of an appointment (even with my insurance). Every treatment leaves me thousands in debt and, eventually, it could lead me to being dropped by my insurance plan. In 2015, I was dropped by a major insurance company and dropped again in 2016 due to the cost of treatment. I've concluded there is nothing I can do to get treatment, apart from going on 100 percent disability. I'm not prepared to do that.

Trudie: Are you part of any advocacy groups?

Ric: I'm on a Facebook page for CVID patients, and that's been tremendously helpful. I'm a big proponent of advocacy groups; I think it would be a great thing to be able to bring awareness about this rare condition to the world using social media connections.

Trudie: Do you often have to explain your health challenges to others?

Ric: All of the time. If I get something simple like an ear infection or catch a cold, it's a serious issue for me; I'll end up in a local emergency room or urgent care. I always ask the doctor: "What is your experience with immune-compromised patients?" If the doctor can't answer, I

ask for another doctor. It's a struggle because you almost have to educate people whose job it is to be educated about this. I do find some things helpful when explaining my disease to lay people. For instance, when my family

hopefully be more research into the genetic components of CVID. Although maybe not in my lifetime, it would be great if there were some type of gene therapy to help patients like me produce antibodies again on our own. There has

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and friends ask, I point them to the Immune Deficiency Foundation's website at primaryimmune.org. There's also an episode of the hit show "House" that does a great job of explaining my condition.

Trudie: Where do you find humor in your circumstances?

Ric: I like to use humor by posting funny pictures to make people think about CVID. I also have been known to quote the movie "Innerspace," which was one of my favorites growing up; there's a lot of neat stuff in that movie about the immune system. My wife has a nickname for me. She calls me "Captain Contagion."

Trudie: What do you most hope for in the future?

Ric: I hope to raise awareness about CVID because with awareness, comes interest, and with interest, there will

to be a lot of change in the way we view chronic and rare diseases. We need a paradigm shift for our lawmakers and government to focus on prevention rather than treatment.

Trudie: Who has been your greatest support?

Ric: My wife, Janet. She's been the reason I get up and go to work on days that I'm able to. We've been together for 15 years and married for 13. She's been my biggest support, biggest fan and best friend.

Trudie: What is a favorite quote?

Ric: One of my heroes, Bruce Lee, said you must "become like water." When water meets an obstacle, like a boulder in a river, it flows over, under and around it. Water always finds a way. ■

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