

# PID Patient Channels Pain of FIGHTING ILLNESS & INSURANCE COVERAGE into Helping Others

**UNLIKE MANY PATIENTS** who learn they have a primary immune deficiency (PID), Jenise Turner was perfectly healthy until her early 30s. She had three children, no health problems and no family history of a PID that anyone could pinpoint. Then the headaches began, followed by frequent sinus infections, and her health got progressively worse.

Eventually, Jenise was diagnosed with common variable immune deficiency (CVID) after having undergone sinus surgery in 2003 and fighting a massive post-operative infection that led to additional surgery. Jenise then developed MRSA, a type of bacterial staph infection that is extremely difficult to treat.

Throughout this ordeal, Jenise's treating physician, an ear, nose and throat doctor, kept reiterating, "this is not normal; this never happens." She was referred to an immunologist/allergist, who eventually diagnosed her with CVID in the spring of 2004.

At the time, Jenise's IgG levels were only slightly low and she did not qualify for treatment with immune globulins (Ig). For the next two years, Jenise was sick all of the time, underwent four more sinus surgeries, and was treated with oral and intravenous (IV) antibiotics, but her health continued to deteriorate. By 2006, she had been so sick and had missed so much work that she lost her job as a registered nurse working in an oncology office. "I loved what I did and was devastated," Jenise said of losing her job.

## Health Declining, Fighting for Coverage

Jenise reached out to her immunologist, who retested her and learned that her IgG levels had dropped into the 500s. However, a new journey was only beginning. Her current insurance provided by her husband's employer denied the Ig treatment for two years, and Jenise's health continued to suffer. She consistently remained on IV antibiotics and was told repeatedly by the health insurance company that Ig treatment was not medically necessary. She ended up getting MRSA again in her sinuses and was referred to an infectious disease specialist who submitted the test results to her insurance company hoping to get the Ig treatment approved. It was not.

"It didn't matter; we had culture reports, operative reports, whatever the reason, it was denied," Jenise said. "The illness had already significantly affected my life, I lost the job I loved and kept getting sicker." Jenise describes the experience as heartbreaking and frustrating.

## IDF Connects Patients

Jenise describes one bright note during this time was that she found the Immune Deficiency Foundation (IDF) and started communicating with other patients. What struck her was that some of the people she met through IDF's network, who were not as sick as she was, were able to get insurance coverage for Ig treatment. Jenise describes her connection with IDF patients as a "real eye opener." "It helped me fight even more," she said.

Jenise started a new nursing job in 2006 at a small hospital, but resisted enrolling for her employer-sponsored health insurance, for reasons she characterizes as just feeling powerless and almost convinced that she really didn't need the treatment. She received her last denial from her original health insurance provider in April 2008, and on the last day of eligibility, she applied for health insurance through the hospital where she working. In three weeks, her treatment was approved.

Jenise started using Ig therapy in August of 2008, however given the severity of her frequent illnesses, it took nearly six months for her to begin to feel better and have more energy. "There were so many low lying infections that my body could finally address," she said.

## Diagnosis of MBLD

Two years after Jenise started on Ig therapy, she continued to contract various infections. Oral antibiotics were not effective and

again she needed to rely on IV antibiotics. At this point, her immunologist conducted additional testing. While Jenise's IgG levels were good, what they did learn was that she had another, extremely rare immune disorder, Mannan-Binding Lectin Deficiency (MBLD), a complement disorder of the immune system that is concerned with innate immunity. "It prevents the body from recognizing it needs to fight infection," Jenise said. When in combination with another PID, it can cause severe illness.

Currently there is no treatment for MBLD, but Jenise says at least she has more answers, more pieces to the puzzle about her health. She explains how important it is for her to be on prophylactic antibiotic treatment, and when she does become sick, doctors treat her more aggressively.

### **Life-changing Illness**

Jenise says in 2010 she had 92 doctor appointments and missed more work than she attended, which inevitably caused her to leave her job. Being a nurse working in a hospital, she was routinely exposed to infection, and her immunologist finally insisted that she stop working in order to protect her health. "Being a nurse is part of who I am," she said. "I've had a hard time finding myself, it's hard financially and I loved being a nurse. What has helped me cope is becoming involved with the IDF as a volunteer."

Jenise describes her first engagement with IDF as talking with

other people who "get it." "It was life-changing," she says. Jenise was able to attend some of the IDF conferences and recalls the emotions of meeting with some of the people she had connected with online through the IDF forum on its website. Now, Jenise is an active advocate with IDF who regularly talks with new patients, advocates on behalf of PID patients and delivers information about PIDs to doctors around her Wichita, Kansas home. 🗨️

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