

Patient Patient

With JEN GENTRY

Alliance for Gout Awareness Patient Advocate



How did you learn you had gout?

After three different trips to urgent care, my foot pain finally landed me in a podiatrist's office. Like the providers at urgent care, the podiatrist initially thought it was sprained. I howled when she tried to put on a walking boot, and that caught her attention.

A 20-something year old female, I didn't fit the mold of a typical gout patient. But after the doctor reviewed my full health record, read some recent labs and noticed I was a kidney patient, she suspected gout. In the end, she gave me a steroid pack and referred me to my nephrologist. He ended up not being the right provider for me, and my gout was still uncontrolled, so I eventually began seeing a rheumatologist. I connected better with him.

How did working with a gout specialist get you on the right treatment path?

The rheumatologist took the time to get to know me, then took more time to explain gout. I've had chronic kidney disease since I was 12, but never knew it could cause gout. I've since learned that gout and chronic kidney disease are closely linked. The rheumatologist said my body had probably been building up uric acid for years.

We talked through treatment options, then he prescribed one medication to help my body get rid of the excess uric acid and another to help keep it from building up again. I eventually took pegloticase, an infused medication, and have been attack free for going on five years.

You need a provider who will listen to you and answer your questions. It's important to find someone who will take the time to learn your situation, what you've been through.

Q How do you manage both gout and chronic kidney disease?

I know some treatments can be problematic for people like me who have both gout and chronic kidney disease. It's something I continue to look out for.

I pay extra attention to keeping both conditions in check. Medication has made that possible for my gout.

Q Did you encounter stigma with gout?

I had to learn to be brave and vulnerable and let people see that living with gout is hard. It's not a laughing matter. It's a serious disease.

My husband saw first-hand how gout totally sidelined my life. But my friends didn't understand. They mocked me for having "an

old man's disease." They thought it was a silly problem, something that I could just wish away.

Then I began calling on them when I was having an attack and couldn't function. I asked for help around the house and help with my son. I let them see how gout kept me from doing just about anything. That's when they finally understood how debilitating gout really was.

Q What advice can you offer to someone with gout?

There's no reward for suffering! There are so many medication options - and there will be one that works for you.

Also, if you think you have gout, learn about the disease so you can be an advocate for yourself. Early on, I didn't know enough to advocate for myself so I kept suffering.

Had I known there was a blood test that could have confirmed my diagnosis, I would have asked for it. It could have saved me years of misery.

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