



Patient Power

A Patient's Story: The Impact of Seeing a CLL Specialist After Starting Treatment

Susan Leclair, PhD, CLS (NCA)

Chancellor Professor Emerita and Patient Power Host
University of Massachusetts Dartmouth

Carol Preston

CLL Patient and Patient Power Host

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Andrew Schorr:

I want to start with you, Carol, and then just go round robin, very quickly, what's a headline you have for our viewers, patients and family members, when they are newly diagnosed that you want to impart to them?

Carol Preston:

Get a second opinion with a specialist. Get a second opinion with a specialist.

Andrew Schorr:

Okay.

Carol Preston:

And the reason I say that, before you go on, is because I did not do that the first time, and as we get into the conversation I'm convinced there were ramifications from that.

Andrew Schorr:

Okay. We're going hear more from you about that. Susan Leclair, a headline for people newly diagnosed. You've corresponded over the years with so many patients, people ask you what's the headline you want to give them.

Dr. Leclair:

Take a deep breath and slowly exhale. This is something that you can take your time with. In a way, you have all the time in the world. This is not a panic. Carol's right. Go investigate the best person that you can have as a physician, but for your family and for yourself, take a deep breath and try and slow down.

Carol Preston:

Here's the difference. We love our local oncologists, and we hope that—and I say this to anybody out there who has CLL or any other cancer with which they're dealing, we definitely would like synergy, we like the coordination between our local oncologist or hematologist and a specialist. But a couple of things happened to me, and probably heard by some of your audience on Patient Power, but I'm going to say it again.

The first was that the local oncologist wanted to treat immediately, and from my perspective, what did I know. I had cancer. He said he offered, you know, had a treatment. Let's get to it. He was recommended, and so that's what we did a couple of weeks after initial diagnosis. The terms out that the regimen that he recommended, and I won't go into all of the history, was an older regimen.

He was concerned—Dr. Thompson mentioned the different stages—I did have stage IV, which meant enlarged spleen and lower platelets, I think anything, according to Dr. Leclair, anything that could go awry was going awry, so it probably was necessary to treat, but it was with an older regimen which lasted a very, very short time. Because his concern was the enlarged spleen.

When I went for my second opinion at MD Anderson admittedly four cycles in, it was with Dr. Thompson's mentor, Dr. Michael Keating, it was suggested to me that perhaps that wasn't the best regimen to be on, although it knocked back the CLL pretty quickly. And so he said we don't change it if it's working. So that's fine.

We mentioned at the beginning that I relapsed three-and-a-half or nearly four years later, and when the genetic testing came back I got that very frightening diagnosis, 17p unmutated, poor prognosis. Poor prognosis. And then I really did think it's curtains, and I best get my affairs in order. Wisely, this time, since I was already a patient of Dr. Keating, I ran as fast as I could to MD Anderson. I sent him the slides, and he said, there's unmutated and there's unmutated. And he said, let me tell you that you have very few unmutated cells.

You're not going to get this from your local oncologist, which brings me full cycle about getting that second opinion. As Susan said, take a breath, exhale. You have time.

And I don't know what would have been had I just stuck with that original genetic report and gone—I don't know what the local hematologist, who's a very fine doctor and I do see him several times a year for blood workup, but I don't know what would have been, what would have been suggested had not Michael Keating talked me off the ledge before Christmas. He said, enjoy the holidays, and he said, come see me in January, and he said you fall within the normal range of treatment, in this case, Andrew, with what you were originally treated with, the FCR. You know, the fludarabine (Fludara), cyclophosphamide (Cytosan) plus rituximab (Rituxan), and so I actually was able to do as Susan suggested, I was able to exhale.

But that's why—you know, I'm going to sound like a broken record—with so many superb CLL experts now around the country, and, Andrew, when you were diagnosed and even when I was diagnosed originally that wasn't the case. By the time I was diagnosed there were maybe six prominent names, and today we have so many more. So there should be some major medical center where somebody can go, if you go for nothing else but that consult. Get that second opinion. These specialists are more than happy to work with your community oncologists.

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