



Patient Power

CLL Patient Shares Story of Second Cancer Diagnosis

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Carol Preston:

Hello everyone. Welcome to Facebook Live. I'm Carol Preston. You and I have chatted many times before, but this is the first time that we are chatting and being together on Facebook, and I'm just thrilled to be here. As many of you know, I have been a CLL patient since 2006, but in December 2017, January 2018, I was blindsided by a second cancer and one that I never expected. So I'm going to recap a little bit for you, but I also want to let you know what I'm going to talk about for the next several minutes.

First of all, finding out about that cancer, which was a total shock to the system, but also how I have been plotting and living my life for the last year-plus. And I want to give you the bottom line right now. It has been a very good, full, purposeful life. I can't tell you how happy I am to let you know that.

So, again, in 2018, actually December 2017, I woke up and felt something pushing against my right glute, to be a little less formal, my right butt, and it turns out that it was a soft tissue sarcoma. I found out pretty quickly, and the reason that I was taken aback and taken by surprise is because as a CLL patient we are taught to expect many, many things. We are taught to look for the signals and the symptoms of a relapse, for example, fatigue, night sweats and so on, and we're also taught to pay attention to other probable cancers, the most prominent of which is melanoma.

So you can imagine that in subsequent years from 2006 and after my relapse 2009, 2010, I was slathering on the SPF, whatever high number I could find and wearing my hats and covering myself, because I knew that melanoma was partial or particular to CLL patients. So I was very, very shocked, taken aback when I learned that I had a sarcoma. I have some theories about why that had happened, and I'll go into that in just a minute.

Something I would like to say, which is very bittersweet for me, I am broadcasting for the last time from my home of 33-and-a-half years in Rockville, Maryland. I have done many a broadcast about CLL with Patient Power from this office, from this room, and today will be the last. We're moving on Friday, May 10th. Some of you may see this before then, some of you after, and the next time you see me, which will be later this month I will be broadcasting from my new digs.

And I'm really excited and looking forward to that, but what can I say. It's emotional and exciting at the same time, so I'm thrilled to have one last chance to broadcast from this wonderful home of 33-and-a-half years, bought, by the way, by a young family, and that's as it should be.

So just a quick recap for those of you who haven't met me, or it's been a while. I was diagnosed with CLL in 2006, treated with one line of chemo, six rounds, relapsed about three-and-a-half years later and treated with another line also of chemo, and that was supervised by my wonderful physician at MD Anderson. So I did start looking around for specialists. And

that's one of the things many of you have heard me say, even if you just get one consult, try to meet with a specialist at a major cancer center or CLL center. So that was in 2010, and knock on wood, so far, so good with the treatment there.

But then came this sarcoma. So in the words of Yogi Berra or maybe in his words, a déjà view all over again, and now what do I do and how do I get started? Well, for better or for worse I did have some experience, so I knew the first thing I had to do once I got the diagnosis and I had the pathology done locally was to decide what my treatment was going to be and where it was going to be. And in the space of a month, four weeks, I managed to get to three major medical centers in Houston, in Baltimore and in Washington, D.C. and did decide to have surgery and radiation at the Washington Cancer Institute, which is part of Washington Hospital Center in Washington, D.C. I spoke with a lot of experts, a lot of radiologists, and figured that that was the best course for me.

So in the space of five weeks I had the surgery, recovered, and then underwent radiation for six weeks. Let me say this about radiation: I felt I had to do it because the tumor was deemed too large to ignore. It really wasn't all that large. It was about five centimeters, and I don't want to get into the weeds on that, but it was important to take care of it.

Now, the question you may ask is, well, you had all of that chemo, and, yes, though I'm not a physician or a researcher, I do feel and suspect that all that chemo may have contributed to the sarcoma, and now I have had radiation. I don't know what the future holds for that, but right now I feel well, I'm doing well, and that was the decision. We all have to make decision as to what we're going to do and when we are going to do it.

So life since that diagnosis. As I mentioned at the beginning, really lots of dynamism in the last 14, 15 months, starting with the fact that before I even finished radiation I made it to my 50th high school reunion up in Longmeadow, Massachusetts. So glad I went. It was a last-minute decision, I wasn't sure I could do it, but what a high and what a lift to see my classmates, and we had such a great time. It was a 36- to 40-hour high, and that was before I finished the radiation, so that really launched me and really helped my attitude as I moved forward.

Because of the surgery and radiation, I had to stop work. I'm a communication consultant. The plus side is I can work when I want. The down side is if I don't work, I don't get paid. So I had to pause for about three-and-a-half months, but just before I finished radiation I did my first workshop. It was very—it was local, so that made it easy. I was successful, and then I went on to do several more.

Before I went back to work, and I'm sure this question crosses many of your minds, all right, I'm 68 years old, why don't I just stop? Why don't I retire? And defiantly I said to myself I'm not going to let the cancer retire me. I'm going to decide. I'm go to choose the timing of when I retire. So I went back to work, and I worked for several months until August of 2018 when I decided it's time to stop.

And I told the office that I would fulfill any commitments that I had, which really took me through just before Thanksgiving of 2018. I didn't renege on any of them and worked to the fullest until it was time to stop. And by the way, p.s., I've actually done a couple of workshops since I retired, so I don't know if consultants ever really retire, but that's really the fun of what I do. And I felt so good about making the decision about announcing when I was going to stop, how I was going to stop, what I would complete before I stopped. So that was also a very positive, uplifting experience, and I would urge any of you who are weighing those options or weighing those decisions if it's in your DNA and in your nature, you decide, and we don't let the disease decide for us.

Just a little fun thing that I'd like to show you all. When I retired, the office treated me to a wonderful dinner. They feted me, and they also presented me with—if I can somehow get this angled correctly—this wonderful caricature of everything in my life including the outer banks of North Carolina, where we have a little place that we can run away to. And if you look really closely, you can see me with my grandbaby, who is now 11 months old, coming up on his first birthday. You can see a microphone, because before I started consulting I was a broadcast journalist for 25 years both on a local and national level, so the office did a fabulous job of capturing my life in this one caricature, and I love it. And it goes with me, of course.

So got through diagnosis, figured out retirement, and then now what do I do? Well, as a journalist, you try to stay independent and not get involved politically, and I said to myself, now I can get involved politically. So I joined a local

political club for women and learned through that club that I could be a senior intern in a state legislator's office. So one candidate that I helped with her election, she was a first-time candidate as a delegate to the Maryland house of delegates.

By the way, she won the primary by 12 votes. I cannot tell you how many people gave me credit for that, but there were lots of people working for her. And I emailed her and asked her if she needed some extra hands, she said great, and so from January to April I spent three months commuting to Annapolis, it's 80 miles round trip, twice a week to work in the delegate's office, and that's how I spent the winter. And such a different experience.

In addition to being that extra pair of hands, I attended lots of hearings. She sits on the environment and transportation committee, so I attended lots of hearings, took notes, and attended hearings on the senate side and just really got to know some people and had a wonderful time doing that. And I'm thinking maybe next winter if I can I might go back one day a week. I'm not sure it would be with this particular delegate, but time will tell as to what I do and how I do it. So that was very uplifting.

And then in the midst of all of that I said to my husband, I think it's time to move. I am proud to say that on my next birthday I'll be 70. My husband just turned 80 in March, and we had a wonderful family celebration for him. And I said, I think we should move when we can move versus when we must move or when we have to move. So in the throes of Annapolis and thinking about the next steps, now all of a sudden we decided to downsize, and for those of you who have been through it you know the nightmare of doing that and decluttering.

There has just been a lot of donations and selling on craigslist and Facebook and through the neighborhood listserv. It's just been a wild ride, and we're not quite done with everything yet, but I would say we're about 80 percent there. And as I mentioned earlier, moving day a Friday, May 10th. So that was really bring about a major transformation.

And so you say, well, then what? Well, you know, we have a chance to kick back a little bit. Unfortunately, when I got diagnosed, we had to cancel a very big overseas trip. That, by the way, ladies and gentlemen, is what trip insurance is for, so please at a stage in one's life one has to decide that trip insurance is definitely, is definitely worthwhile. So we haven't planned any major overseas trips yet. It seems that we've been tripping over all of these very positive events in our lives.

And, by the way, one of the other thing that I want to mention is that after I was diagnosed I decided to let my hair go natural, which is a nice way of saying gray. But my hairdresser, who was vehemently against it at the start, decided, and she said, you know, gray is really the new blond. So I'll take her at her word, and I feel very liberated in not having to—in not having to do anything with my hair except wash it and dry it.

So one final thing I want to mention before we wrap up, and that is that while I was in Annapolis I got very involved in the Aid in Dying movement in Maryland, and that actually is what my next video blog is going to focus on. I got pulled in ways that I never dreamed I'd get pulled in.

So I want to leave you with the fact that despite the diagnosis it has been a very uplifting for the most part 14 to 15 months, and I look forward to chatting with you later this month about medical Aid in Dying. So for now, I will say to everybody stay well, live well, and this is so long from Carol Preston.

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