



Patient Perspective: Ways to Stay Proactive During CLL Watch and Wait

Cathy Hamilton
CLL Patient

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Andrew Schorr:

Cathy, let's see if you're willing to share a little bit for you, and we're going to discuss how it's different for everybody. So when they did your blood test do you recall what the white count was initially, the white counts?

Cathy Hamilton:

Yes, so I would just say I'm the first patient that Dr. Phil—sorry, Dr. Phil—mentioned. I had a very low white blood, I mean, relatively speaking my white count at the start was just 12.8, and at my last follow-up it was down to (inaudible) .1. So, again, I have a just a smidge of CLL I call it. I'm not symptomatic. They were just—they were high enough for someone to sound the alarm, but really it's not that I've been told I have the good kind of cancer, but I have been told I'll probably die with it, not from it. I don't know what consolation that is, but, you know, my numbers are not that scary.

Andrew Schorr:

And how often do you have a blood test?

Cathy Hamilton:

Well, I'm not going back until May now, because I'm going to have my blood checked at my annual physical. So it was three months, then four months, and now it's not until May at the oncologist's office.

Andrew Schorr:

Okay. And have you had this, Jackie referred to, this FISH testing or any of these other more sophisticated tests?

Cathy Hamilton:

Not yet. That's in the plan for next year. I had a very positive I think it's called CD38 marker from the flow cytometry test that he said was really good prognostically, but that's really all I know. I'm just kind of—I'm just spreading out the expense part of it.

Andrew Schorr:

Right. And you've had a bone marrow biopsy or not.

Cathy Hamilton:

Not.

Andrew Schorr:

Okay. All right. So we're going to go on. Oh, swollen lymph nodes or night sweats?

Cathy Hamilton:

No, and that's what I was told my oncologist. I want to hear from you immediately if you have drenching night sweats, debilitating fatigue, swollen lymph nodes. He checks my spleen and all my lymph nodes every time, and so far so good on that count. I will say I do intend to find a CLL specialist. There doesn't happen to be one in my area.

Andrew Schorr:

You have two on camera with you right there.

Cathy Hamilton:

I know, so I'm pretty much halfway between MD Anderson and the Mayo Clinic, and then my son just moved to Denver and I know there are a couple of experts out there. So my big thing right now is trying to figure out where I'm going to live in retirement and then finding a CLL specialist close, so that's going to take about a year to figure out.

Andrew Schorr:

Yeah. And I'll just mention for me. So I'm living with two blood-related cancers, CLL, which I've been treated for twice, and so I chose to be in San Diego to be near Dr. Tom Kipps of UC San Diego. I have another condition, myelofibrosis, and at that same center they have a specialist in that. So that's kind of where I chose to be living my internet life here with Esther.

So one other question for you, Cathy, and then I want to probe our medical experts further. And again send in your questions to cll@patientpower.info.

And that is so you've been told there's like a scent of smoke in your kitchen somewhere but there's no fire and you don't have to worry about it. How have you coped with that?

Cathy Hamilton:

Well, I wasn't ever going to be happy with sitting around doing nothing, so I really did take—I read up a lot. Patient Power, I have to say, brought me up the learning curve—which is very steep, by the way—it brought me up that curve very quickly. And I am grateful to you and Esther and your whole team for that, because I think it would have taken months without the internet to think about what I was looking at.

And I just decided to make some lifestyle changes that I thought would just make me healthier in general and perhaps fend off those secondary cancers that we worry about when we have CLL. So I had all my necessary screenings done and I switched my diet and I started to exercise more faithfully. I'm taking a couple of supplements, not crazy stuff, but I just got healthier.

Andrew Schorr:

Sunscreen, although more for me in California than you in Kansas.

Cathy Hamilton:

Oh, I've had precancers frozen off my face. I went in immediately and had a full body skin check. I had a mammogram that I was about nine months late on, and I'm getting a colonoscopy on schedule next year. So those are just the kinds of things that—I don't think watch and wait means doing nothing. I think you can do things to make yourself healthier in general and just be more proactive, and I think that gives you a sense of control and empowerment versus just wait to see what the universe is going to deal you, you know.

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