



# Sue's Story: How Getting a Second Opinion Changed the Course of Care

**Sue**  
CLL Patient

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**Carol Preston:**

Sue, could you share with us how you got—how you got into this coffee clutch with this morning, this afternoon?

**Sue:**

Absolutely. When I was first diagnosed, again I mentioned it was just through routine blood work, and my family physician said, you know, you're either really, really sick with an infection or you have leukemia. And he said, you look too healthy to be having a really bad infection.

So he referred me to a local oncologist, and they started monitoring me. And during this time I was really quite ill, and it was progressing very, very rapidly, the white blood counts, everything. And this was from February until the first of June, and I went to see the oncologist, and he said we need to start treatment right away. We're going to put you on FCR.

And I for some reason decided, I said, would you please give me a couple of extra slides of my blood work. And he did. He said, yeah, I'd be happy to. What are you going to do with them? And I said I'm going to send them to a friend of mine who is a CLL research—he's a blood cancer researcher at the Huntsman Institute in Salt Lake City. And I sent them to him.

He immediately wrote back and said, do not start treatment. Get a second opinion. He said you are—I don't know if you can get in to see Dr. Kipps, but he's the best one close to you. So I cancelled my appointment to start treatment. I called down to the UC San Diego in La Jolla. I said they want to start treatment, and they said, send us all of your paperwork. I sent a fax, and within 45 minutes after I sent the fax I got a call, and they said, the doctor wants to see you next week.

**Carol Preston:**

Wow.

**Sue:**

Yeah. He wants to see you next week. So off I went. It's about a two-hour lovely drive from Palm Desert to La Jolla, which is even prettier. And so I went down there and am seeing Dr. Kipps. He immediately started my treatment

with apheresis. Because my spleen was so enlarged, he was very concerned about tumor lysis syndrome. So my first step was to go back down to the hospital and spend the day having the apheresis where they take your blood.

**Carol Preston:**

Yeah, would you explain what that is for us?

**Sue:**

Well, it's kind of—they take all your blood out of one arm and put it back in the other, and it's kind of like a dialysis except they put it into a centrifuge, and that spins out the white blood cells because they're heavier, I believe heavier than the other blood cells, and they were accumulating in a bag—although they're not white, they're pink. I will tell you that right now. And they were accumulating and it took—it was about a six-hour process, and they...

**Carol Preston:**

So, Sue, if I may jump in.

**Sue:**

...yes.

**Carol Preston:**

So good news is that you did push for that second opinion.

**Sue:**

Absolutely.

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