



Patient Power

Exploring CLL Treatment Options: Finding the Most Effective Care

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Andrew Schorr:

So, Dr. Wierda, so we alluded to this sort of changing array of treatment options in CLL and the nuances today. It seems like it's more than ever now. In your career you've seen so much change, and you at MD Anderson you mentioned vaccines and such, you have a window into what could be next. You and I have talked about refinements in CAR-T therapy. Sort of CAR-T version 2.0, can that be more affordable for a wider array of patients. So how does someone--how did does a patient--they can't keep it all straight themselves, so how do they have this ongoing discussion with their doctor about what's right for them?

Dr. Wierda:

So it depends on if they're being followed regularly by their community oncologists or by their specialist, so the discussion about keeping up with what's new and ongoing in the clinical trial area, that discussion should happen with the specialist because the specialist will have clinical trials available for the patient that they won't be able to get access to in the community.

Most of the time the clinical trials are not done in the community. So the discussion should be with the CLL specialist about clinical trial options and what's available not only with that particular specialist but what may also be available at other centers and what's interesting and what's exciting, what people are hearing about and talking about.

When I'm interested in looking at what's open in clinical trials I go to clinicaltrials.gov. [Clinicaltrials.gov](http://clinicaltrials.gov) is a website that the government maintains that is current with regard to all of the active, ongoing clinical trials, Phase I, Phase II, Phase III clinical trials. So with that website you can pull up any trial right now that's active and ongoing. It has a search engine, and you can do a very good search with it. You've got to know the terms to use and what you're looking for, but it's a very good source if you're interested in doing some searching on your own.

But I think the discussion really should be with the specialist. And, you know, we have meetings, we have ASCO, with we have ASH. We hear about preliminary reports from clinical trials, Phase I trials. We hear about activity with, for example, CAR T-cell therapy and those. So we have two CAR T-cell trials open here. We didn't have that, say, a year ago. So we

were hearing about the activity, and there were centers that were doing CAR-T work, so for patients who were refractory at the time we were referring them to Seattle or to UPenn to enroll on one of the active studies.

We have a lot right now of studies for patients who have failed standard treatments, who have failed ibrutinib (Imbruvica) and/or have failed venetoclax (Venclexta). We're having difficulty enrolling in those trials right now because we have a lot of them, and patients are doing very well and there's fewer patients today than we had, say, three, five years ago who had had standard treatments and needed something new. So it's an important discussion to have, and it's best to be had with your specialist rather than your community oncologist.

Andrew Schorr:

Well, the good news is, as you say, many people are doing well, and we have two patients, one on venetoclax, one on ibrutinib right here who are doing well and me, who had infused therapy with obinutuzumab, or Gazyva, doing well after having FCR years ago.

So we have different stories, and I think that's one thing I wanted to get at. Each of you patients, Bob and Michele, you talk to other patients, and wouldn't you agree that what people have to hear is that your story may be different from mine. What works for you may not work for me or vice versa. We may have different side effects. Bob, do you tell people that, that it's not a one-size-fits-all?

Bob Azopardi:

Exactly. You're exactly correct, Andrew. You know, from the people I have met--it's been a long journey, and I hope this journey continues. However, you know, when you're sitting in an atmosphere of having, let's say, chemotherapy, if we go back to that for just a second. Chemotherapy works different on everyone. I had somebody sitting next to me who was doing fine, and I got deathly sick on Rituxan after I had taken 15 treatments of it, so go figure that. So you really never know. It's not defined and put down in stone that my side effects to any of these drugs and/or trials is going to be the same as someone else's.

Andrew Schorr:

Absolutely. So, Michele, listening to this what would you say to people today so that they get what's right for them? We have more sophisticated treatments. We have even a variety of thinking sometimes among the specialists, and we have a moving target of medical science moving forward with all of us hopefully having a very long-term condition. So what do you tell people?

Michele Nadeem-Baker:

For those who are newly diagnosed, I generally say to them that things have changed, that there is so much out there already to treat them or in the pipeline that it's important to get, if you're comfortable with it, on a clinical trial to get tomorrow's treatment today, which, as Dr. Wierda was saying, is available at the different larger centers or to go in for a consult on that. Go to clinicaltrials.gov to find the clinical trials in your area.

But the other thing is, I'll reiterate what Bob was saying, it is not one size fits all. The three of us here probably all have different genetic indicators, like I'm 11q IGHV unmutated. I know you're different than that, Andrew, and Bob, I'm not sure.

Andrew Schorr:

We're mutated.

Michele Nadeem-Baker:

So that also I know goes into what's going to be more effective for you versus me, and then there are other factors as well. So to have the big picture, to understand what you have is also the other integral part, to understand what it is they've got. You don't just say I have CLL, as we know, just three of us here. As patients there are all sorts of varieties of this disease. So that's also good to know yourself, what there is, so that when you're starting to research things you can see what's happening out there and what would be best for you.

Andrew Schorr:

Yeah. So we call this the Partners series. So I have my ongoing discussions I did with my community oncologist who is very dedicated to CLL as well when I used to live in Seattle and I was in a long remission, and we would have these ongoing discussions, just like Bob said. What's changing? What could be an improvement for me should my remission end? Or if you're in watch and wait what's changing and what applies now?

And we kind of became friends, and Bill, I'm sure, thank God, with many of your patients now, you're still a relatively young guy, but some of the people you've known for many years. I mean, you've known me for many years, and so that truly can be a partnership with your provider on kind of a continuing discussion of what's right for you at different points along the journey.

Dr. Wierda:

Yesterday I saw three patients in the clinic who I had seen for 20 years since I started working here at MD Anderson. That's just in one day. So now more than ever we're having very long remissions and very good outcomes, particularly with the newer agents where you're exactly right, patients—and my opinion these days is that the lifespan of an individual with CLL, particularly for people who are over 65, 70, their lifespan should be and probably is what it would be if they didn't have a diagnosis of CLL, even if they need treatment. And that wasn't the case 10 years ago.

Andrew Schorr:

Wow. And on the flip side, frankly, we do get emails from some younger people, and I'm sure you see them with CLL, but the landscape of what you're doing in research could well pay off for them to hopefully give them such a long life as well. Wouldn't you agree?

Dr. Wierda:

Absolutely. And we are very excited. Most recently we've been doing a lot of work with combination trials and getting extremely deep remissions with the combinations that we're testing, for example ibrutinib plus venetoclax. We won't know for a few years how much of an advance that is, but we will eventually have that data. So on the clinical trials that we're doing now we think that we are achieving better responses, better depths of remission and fundamentally changing the biology of the disease and the outcomes for patients with CLL.

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