



Patient Power

Understanding the CLL Treatment Landscape: Getting Educated and Speaking Up

Mark Silverstein
CLL Patient and Advocate

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Andrew Schorr:

Mark, one last thing I want to ask you about is: you're a big believer in education and you've had many long chats with your hematologist as you plotted what might work for you when an earlier therapy was kind of pooping out on you and you needed something else. What would you say, with the CLL landscape now, on the importance of patients being educated and speaking up and having that two-way dialogue with their doctor?

Mark Silverstein:

I can't say enough about it. From my perspective, once again, the proof is in the pudding. And for me, like last year when I suggested adding rituximab (Rituxan) as a combination to venetoclax (Venclexta), that was my self-advocacy at work. You know? It pays. It pays to understand the treatment landscape. It makes you a partner. It doesn't just—it's not the doctor just telling you what to do and suggesting it. Sounds great. And it's not that I don't have faith. I love my hematologists and I have a lot of faith in them but it doesn't mean that he knows everything.

And especially a generalist. I understand that, especially in the U.S., there are a lot more specialists for CLL, but in Canada there isn't a lot. So you tend—the chances are, you're seeing more of a general hematologist. And as great as they may be, they can't know everything about everything. And so I took it upon myself to understand my treatment landscape well enough, so I could challenge and I could question and we could sit there and map things out. What happens if this happens? What happens if venetoclax doesn't work?

I haven't seen my immunologist since transplant but I probably will see him sometime in the next two to three months and I'm gonna ask him, "What happens if this stops working? What's our next step?" Just so I know. I have a sense of it. I mean, I already have a sense in my head. I'd probably go back on venetoclax and rituximab because I didn't fail on it, I just stopped using it because of the transplant. However, maybe that's not the right thing at the moment. So that's a discussion to still have.

So it hasn't stopped because of the transplant. I still keep on top of everything. I'm still trying to understand where the landscape is going so I have a sense of what next steps are if necessary.

Andrew Schorr:

Well, we always say knowledge is power. Mark, I'm so grateful that we could have this conversation three years after we met before when you were needing treatment again and that we're at day 250+ and you're feeling pretty good. And I wish

you all the best for a long life. As I said in 2015, I said, "Mark, we're gonna catch up with you down the road." And we will again and I hope you'll be feeling good as you are now. Mark Silverstein, from outside Toronto, thanks for being with us again on Patient Power.

Mark Silverstein:

It was wonderful. Thank you.

Andrew Schorr:

Andrew Schorr with Mark Silverstein. Knowledge is power. And, remember, knowledge can be the best medicine of all.

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