



Patient Power

Mark's CLL Journey: FCR to Combination Therapies to Transplant

Mark Silverstein
CLL Patient and Advocate

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr, and it is a thrill for me to connect myself and you back with Mark Silverstein, a CLL patient of many years who we've interviewed before back in 2015. He joins us from Aurora, Ontario, outside Toronto. Mark, welcome back to Patient Power.

Mark Silverstein:

Hi, Andrew. It's nice to see you.

Andrew Schorr:

So, Mark, you've had quite a journey. When we spoke to you in 2015 at a conference of CLL patients from all across Canada, you had big bulges on the side of your neck. You had had treatment earlier for CLL and then things were going south again. So I believe originally you were diagnosed in 2011, was it?

Mark Silverstein:

2010. At the end of 2010. It was like December of 2010.

Andrew Schorr:

Okay. And then you had the FCR treatment, right?

Mark Silverstein:

I was diagnosed with stage IV SLL. I had six rounds of FCR and was basically in remission until November 2014. October or November 2014.

Andrew Schorr:

Okay. And so you had this dialogue with your doctor and that led to being treated with ibrutinib (Imbruvica). So that worked for a little while?

Mark Silverstein:

Ibrutinib (Imbruvica). Certainly we always talk about options. My wife, Nelia, has a video of the first two or three days of taking ibrutinib. And as you talked about my nodes, how large they were, it was amazing how quickly—like within two days, 50 percent of the size of my nodes went down with the ibrutinib. It really was spectacular when we

first started taking the drug. Unfortunately, the drug only lasted for about 14 months until 2016, the kind of September, October-ish timeframe once again of 2016.

Andrew Schorr:

And what happened then?

Mark Silverstein:

There was a slow relapse or at least it started a little slower. So I think it was around October-ish, November, we found out I was relapsing. By the end of February, I was in the hospital for three weeks. White counts were at 400, close to 400, and I was pretty sick.

Andrew Schorr:

Okay.

Mark Silverstein:

It was the first time we heard the hematologist say that he was concerned that—he was concerned.

Andrew Schorr:

Okay. So you're running through your options and what was available in Canada. So what did your doctor and you agree to do?

Mark Silverstein:

So it was time for—I was fortunate that venetoclax (Venclexta) had just been released on compassionate grounds about—I think it was just literally a couple of months before I was in the hospital. So it was on to venetoclax. But it took a while to get—it didn't work right away. It took some time to get control of the CLL. I think it was close to being a runaway for me. Perhaps if I didn't have venetoclax, it was something else, it might have not gone as well.

But eventually the venetoclax started kicking in and started getting my counts down again and got me well enough to sort of start thinking about other things. And I had read quite a bit before I actually ended up in the hospital in regards to a combination of rituximab and venetoclax and how much it improved the efficacy of the venetoclax, adding the rituximab (Rituxan). And so I suggested it to my hematologist and said I really think it's a good idea, I've read a lot of statistics on it, etc. He wasn't overly familiar with it at the time.

However, within a short time, he ended up at a presentation by, I think, a doctor out of the UK, and they actually discussed it, and he came back to me literally a couple of days later and said, "Okay, Mark, I saw what you were talking about and let's start doing it." And I honestly believe that that was part of the reason I got to the bone marrow transplant as well as I did.

Andrew Schorr:

We should mention that, as we produce this program, the Rituxan/venetoclax combination was in a new trial and has been approved here in the U.S. for many CLL patients and probably will be used more widely. So you got that combination. How long did that last for?

Mark Silverstein:

So I started venetoclax in the end of February timeframe. We didn't start rituximab actually until I'm gonna say August. August of that year. Unfortunately within Ontario, we had some challenges. I mean, our doctor basically said, "I'll get you a chair in the hospital but you guys have got to figure out the rituximab." Due to the way our healthcare system works, I had rituximab in my initial treatment with FCR and so the government doesn't cover it after the first use. We had to start figuring out how to arrange for it financially.

And it was certainly worth it but it was a little challenging and it took us some time. And it actually started me a little bit on my advocacy work in regards to speaking at the Step Lymphoma Conference and at our local Queens Park, where our municipal government is, talking about access to drugs and the cost of those drugs.

Andrew Schorr:

Right. So you were doing this combination but yet in the fall of 2017, you ended up having an allotransplant. What led to the need of the transplant?

Mark Silverstein:

When we look back at it, Nelia and I have talked about it a couple of times—more than a couple of times. And it was always I could go back to my first discussion with my hematologist seven or eight years ago and it was talked about. But I don't think we ever really took it seriously until I relapsed and wound up in the hospital. I mean, we came close enough and it relapsed quick enough and, not strong enough, but with enough force and enough overwhelming sort of—the CLL was out of control instead of controlled.

And I can very much see that and my concern became that the next time I relapsed—and I knew I was gonna relapse no matter what I was on. Whether it was venetoclax or rituximab or whatever else it was gonna be, I was gonna relapse sooner or later. My fear was that there was gonna be no coming back from it. And so right after I got out of the hospital, I think it was a week after I was out of the hospital in March of 2017, I was already at the transplant doctor's office, and we were already having a chat. And there was kind of no looking back after that.

For me, it was, as much as I had played the chess game up to that point of, "Okay, let's wait for the next drug and let's wait for the next drug," I think the relapse, that last relapse, really scared us. And we have a—there's a CLL specialist in Toronto. Her name is Kristi Chen. And she's really the only kind of real, real specialist for CLL within Toronto. And her words kind of echoed through our heads all the time, which was sometimes even though—that she's seen people two weeks prior looking well, they relapse, and they actually passed away with two or three weeks. It just—their CLL becomes out of control and they just can't get it back.

And so that also kind of rang in my head very true and, based on my experience, it made sense. You know? There was a little spot about CAR T, but unfortunately in Canada it's—they're just beginning to set up for clinical trials and coming to the U.S. to do it was challenging and also it's way expensive. So the allotransplant seemed like the best route to go. And actually statistically, at least at the moment, I think there's a better chance—I think the allo has a 50 percent chance of being effective and I think CAR T still for CLL is only in the 30 percent range. So statistically it was perhaps a better choice.

Andrew Schorr:

Well, Mark, as we interview you now in July of 2018 and you began the transplant process in the fall of 2017, I think you're at Day 250+, having had the transplant, and you look well and we're having this conversation. How do you feel now? I mean, a lot of people don't see transplant patients much now. They're not exposed much. But you had this long road. How are you doing? How are you feeling?

Mark Silverstein:

Overall, I feel pretty good. I certainly feel fortunate. I've also been fairly fortunate that there's something called graft versus—for those that don't know, there's something called graft-versus-host disease, which is a huge part of post-transplant challenges. And I've had very little of it. I had a little bit of a skin graft versus host, maybe a little bit in my guts, but really nothing major. And so beyond fatigue and energy levels, strength kind of stuff, I'm doing okay. Cognitively, I'm catching up a little bit but overall I'm doing okay.

Andrew Schorr:

Well, that's great. Now, we should mention that, as you began your CLL journey years ago, you decided to have education to become a therapist. And so much of your practice over the years, when you've been well enough, has been working with cancer patients. So tell us about your devotion to helping other people where you've been living it yourself.

Mark Silverstein:

Yeah. After FCR, after six months of FCR, I just—I realized that a lot of cancer patients actually experience this. You're just—you've got your game face on, so to speak, and you try to get through the treatment part of everything. And then all of a sudden there's this—you're left holding this emotional/spiritual baggage of what just happened to you. And I just think that the diagnosis, going through treatment, it all has an impact and it's what you sort of do with that impact. I found my need to talk to people who understood what I had gone through was huge.

And I got lucky enough to find a group for survivors called "Picking up the Pieces." And it's just a wonderful 10-week program, just to sort of help you figure out what you just went through and how to sort of pick yourself back up, spiritually and emotionally more than anything else. I found the effects of having your life out of control, so to speak, the effects of understanding in a different way that I'm gonna die in a different way than I understood before my diagnosis, all those things have had an impact on me. And I think they have an impact on many people.

And I think you kind of wake up and go, "I want to do something different. Life's short. I need to do something that's more meaningful, that brings me more value in my life." And so after going through the program myself, I realized this is really what I want to do myself. And so I went back to school to become a therapist. I actually co-facilitate that group now with the psychotherapist who is kind of my mentor at this point.

And I also managed to create my own group for terminal cancer patients. So to deal with people with no treatment options left. And that's where I'd like to kind of bring my focus back to a little bit. I did some work prior, a while ago, but I haven't worked with people in that situation for a while and I'd like to get back to it. I think it's a really hard thing to go through but the bravery and the things I've experienced with the people who are terminal are just – it's just been amazing. And it's just an area that I'd like to refocus on once I get back.

Andrew Schorr:

Well, I just want to tell you how—I'm sure I can speak for many, how grateful we are that someone who has lived it is giving back and gets the training and now brings the wisdom and support to help all of us as we go on this journey. You told me in 2015 and you mentioned it earlier in this interview about the chess match of treatment choices. And so at this point, Mark, do you feel like you're winning the chess match?

Mark Silverstein:

It's funny. When you said that, I was thinking it was winning in some ways. I'm not sure yet honestly, Andrew. I'd like to believe I am. I think I made a good choice of having the transplant. I think I've given myself an opportunity. To be honest with you, since ibrutinib, I've been on some sort of cancer medication for the last two or three years. So it's really been nice not to be on any medications. I've noticed a difference in how I feel. My cognitive abilities, everything is just better.

It's one of those—this is a bit of a marathon, the transplant. So it's a time thing as well. So as much as I'm thrilled that currently my bone marrow biopsies are clear and that my counts are really good and that my transplant doctor is certainly talking about perhaps I've been cured, it's some time. You know? And I would love to grab on to that and hold it tight.

But I think it's also—CLL over the years has taught me that it's a pretty tough customer as well. And I think I need some time to really—I think there's a two-year mark that kind of statistically means that there's a better chance that

I've been cured. And then there's a five-year mark sort of thing. So it's a bit of a time thing right now. As much as I want to believe I'm totally cured, I can't quite go there yet. I just—right now, I just consider myself in remission and, as time goes on, I'll start ticking closer to that “cure” word but I'm not quite ready to say that at the moment.

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