



Patient Power

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Andrew Schorr:

Eliot, let's go back over your situation a little bit. So, I was diagnosed in 1996 and treated in the FCR trial in 2000 and 2001. I've only had infused therapies, and I went 17 years through remission, and then I got obinituzumab (Gazyva), which I know you're gonna tell us you received along the way as well, but I've never had an oral therapy for CLL. I do take an oral therapy for another condition, ruxolitinib (Jakafi), and I'm on Medicare, Medicare Part D, and I have substantial co-pays, and I still work, so it's not cheap. Eliot, what's your CLL situation? When were you diagnosed?

Eliot Finkelstein:

I was diagnosed in May of 2013. I had no treatment until January of 2016, and at that time, I did have CR for six months.

Andrew Schorr:

Okay, didn't last for you. And, I know you developed some pretty significant skin issues, right?

Eliot Finkelstein:

Correct.

Andrew Schorr:

And then, what other treatment have you had?

Eliot Finkelstein:

Well, it was about six months after I finished my FCR. They put me on ibrutinib (Imbruvica), and it worked really quickly, really well. But, three weeks after I started, I started having skin issues, and they thought it was related to the ibrutinib, so they stopped the ibrutinib, put me on prednisone, and that started my journey for my skin issues – my autoimmune skin issues—and that took until August of 2017 to diagnose. Going every other week down to Mayo, which is a five-hour drive.

Andrew Schorr:

In Scottsdale, Arizona. Well, lots of doctor visits now. What treatment have you had since then for the CLL?

Eliot Finkelstein:

We only really started the CLL treatment because the dermatologist said my skin issues are from my CLL, and so, we started, and my doctor put me on venetoclax (Venclexta) and obinituzumab, so I did the six months of obinituzumab.

Andrew Schorr:

Obinituzumab, or Gazyva.

Eliot Finkelstein:

Right, "Gazyva" is easier to pronounce.

Andrew Schorr:

So, you had the obinituzumab, and now you continue with the venetoclax, trade name Venclexta—you're continuing with that. How are you doing?

Eliot Finkelstein:

Right. I'm doing great. I haven't really had any side effects whatsoever. I was on 400 for about 15 months, and we dropped me down to 300, and still haven't had any issues whatsoever.

Andrew Schorr:

Okay. Let's talk about the financial side of it. You've had some hassles related to all these different doctor visits, procedures, and things like that, right?

Eliot Finkelstein:

Correct. The biggest things are—part of it was billing from the insurance companies, part of it was they claimed I did not get pre-approval, and the easiest one to say is when I went in for surgery, I got my doctor's approval, they got the insurance approval, come to find out the anesthesiologist was not approved under the insurance, and they expected me to pay that, and I said, "No, I'm not paying that."

I did what I was supposed to, and I filed for appeal, and one of the times, they said, "Well, we're not going to approve it." I go, "Fine, give me all my documents, and I'll take it to the state appeal," because my Blue Cross/Blue Shield was out of the state of California under the CalPERS, and the next appeal goes up to the state, and once they heard that, they decided to pay it. So, it's just like you have to keep fighting it.

Andrew Schorr:

We're gonna talk about that. And, related to your co-pays for your venetoclax or even ibrutinib, have you had difficulties with that?

Eliot Finkelstein:

Not really. My doctor seemed to be approved. I'm seeing Dr. José Lis, if that's okay to say.

Andrew Schorr:

Right, but not the doctor visits—the co-pays for the medicine.

Eliot Finkelstein:

Right, right. He got it approved, and he made the phone calls to the insurance companies, and also the approval, so in that respect, my leukemia medications generally have not been a problem.

Andrew Schorr:

All right. Stacey, first of all—so, some of us need medical procedures. We have doctor visits, get second opinions, so first of all—then, they say—or, even when he was asleep in a surgery procedure, there was an anesthesiologist I kind of sensed was out of network –

Eliot Finkelstein:

Correct.

Andrew Schorr:

No control over that.

Stacey Worthy:

Right.

Andrew Schorr:

So, tell us about this appeal process a little. Is it just—he just had to really speak up for himself and take it up a couple of levels. What would you say about that?

Stacey Worthy:

Yeah, absolutely. You always have to be your own advocate and make sure you fight. Appealing is the best way to get coverage. It is common to have these surprise bills when you're getting treatment at a hospital because, as was the case here, one of the providers in the hospital—even though the hospital may have been in-network, the provider was out-of-network. There are states that are starting to enact laws to prevent those surprise bills, but not every state has

enacted those.

So, do exactly what you did, Eliot, and that is appeal. So, typically, the appeals process starts with an informal conversation with your insurer. Then, typically, you may have to file a formal appeal with your insurer. At that point, if they deny you, you have the ability to request an independent review by a reviewer who's not affiliated with your insurance company, and at that point, if that is denied, then you can always file a complaint with your insurance commissioner or state attorney general.

And sometimes, all it takes is a threat. So, you call them up, you say, "I'm gonna appeal, I'm gonna file a complaint with my insurance commissioner," and they switch it like that. Another way to get them to approve the claim pretty quickly is to go to the media. If you have a pretty egregious case and you talk to a reporter, or even through social media, and you let people know what's going on, they don't want that bad publicity, so they're gonna change that decision pretty quickly.

Andrew Schorr:

I'm just gonna give an example that's not really a medical one, but my kid was a student at the University of Oregon and transferred, and somehow, not the dorm, but one of these off-campus apartment buildings that are pretty expensive had on record that he had signed something at 19 years old that he was gonna be a tenant again, and then we started getting bills.

He'd left the school months before, and I had guaranteed it for his first year, but I hadn't guaranteed it for the second. In the state of Oregon, it's not required that the co-signer be made aware that there's this renewed financial commitment by a minor, basically—or, if he was—and I raised hell, and I said, "The parents of the university would be really upset if they knew this. This is not right, and we're gonna go to the state legislature and the governor if we have to to change it." So, guess what? They dropped all the charges.

So, all I'm saying is speak up. I don't think you have to be a media celebrity, you're saying, but you have to threaten it—that you have something like this whole thing—the anesthesiologist being out of network—you never met the anesthesiologist, perhaps.

Eliot Finkelstein:

Exactly.

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