



Accessing Financial Support for CML Medications

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Andrew Schorr:

Hello and welcome to Patient Power on location in San Francisco at the American Society of Hematology meeting. Andrew Schorr with my friend, Greg Stephens.

Greg Stephens:

Yes, sir. Hello, Andrew.

Andrew Schorr:

Greg, welcome back. Greg, of course, is a partner of ours. He's the founder and the executive director of the National CML Society. We're talking about CML. Of course, what a success story over...

Greg Stephens:

Absolutely.

Andrew Schorr:

...many years now, where so many people were before that, you know, the outlook was not great. You can take a pill and live hopefully a long, natural life span. Not always without total side effects, but you can live and you can be with your family and you can work, and that's worked for most people. But, Greg, let's talk about the other part of this.

Greg Stephens:

Ah, yes.

Andrew Schorr:

As you live taking expensive medicine there are costs, and that's been an issue in CML. Maybe as a pathfinder for other conditions, because I have a different chronic condition, my medicine is \$8,000 a month.

Greg Stephens:

Yes.

Andrew Schorr:

So talk to us about costs. It's a concern.

Greg Stephens:

Well, we know the world of advocacy around CML is dramatically changing because the disease is being treated as a chronic condition, and now, as you say, many patients—most patients, all patients for that matter can anticipate a normal life span as long as, you know, adherence is done and proper monitoring and treatment is administered as it should be.

You recall last year we were talking about cessation trials. That's the big thing right now. And, of course, when we talk about cost and cessation, we realize that there is a—there is almost a light at the end of the tunnel for some individuals. However, for those individuals right now who are either in the process of learning about their diagnosis, getting a control over the disease through treatment, those costs are constant, and as a result there are some hardships that come along with that.

Even for patients who have been diagnosed for a long time who are perhaps not a candidate for a stopping trial, we know that treatment is going to have to continue for a lifetime. So with that comes the challenges of trying to afford now this wonderful treatment that gives that life. As you said, years ago, probably 15 years or more, before the advent of TKI therapy...

Andrew Schorr:

It wasn't chronic.

Greg Stephens:

...yeah, it wasn't chronic, and so now there are these new challenges. How do we afford a lifetime of treatment? Some of the things that come along with that, not only in securing funding to purchase that or assistance or making sure our insurance covers all the testing that's involved, is the fact that many individuals, it can impact—it can impact their adherence to the drug. We get calls...

Andrew Schorr:

Yeah, cut your pills or skip doses.

Greg Stephens:

Yeah. You know, you skip, skip doses, and what we've learned is that as few as three doses missed per month can have a dramatic impact on your ability to achieve those deep levels of response. But in order to stop therapy, you need to have those deep levels of response, so we're trying to balance. It's a juggling act.

Andrew Schorr:

Okay. So, Greg, what are we doing for assistance? There are assistance programs through the National CML Society. You can help connect people, help them understand that there's still going to be some pain, certainly for almost like middle class people.

Greg Stephens:

Yes.

Andrew Schorr:

They're not of low income, but they have mortgage payments, they have a kid in college, whatever it may be, and they say oh, my God, how do I make a choice between taking this little pill every day and paying my other bills?

Greg Stephens:

Absolutely. That becomes discussion around the dinner table quite often here in the States. We know that, as you say, there are a variety of assistance programs out there for individuals taking the drugs, but there is a large number of people that fall outside the parameters...

Andrew Schorr:

Right.

Greg Stephens:

...of those programs. So how do we best approach that and provide resources and insights into how they can navigate that? One thing we've learned is a key word, a gatekeeper word when we're talking with our insurance companies is "underinsured," and many times we'll get calls from individuals who have been talking with their insurance company and arguing over whether that drug is covered and to what extent that drug is covered. And sometimes simply say I am underinsured when you speak with an assistance program will—is a gatekeeper word and will open you up to a different level of management for that program, and they can offer perhaps options.

Many of the pharmaceutical companies have foundations that go above and beyond what those assistance programs. Now, there [are] no guarantees. However, if you can get to those people to talk about what other options are there out there, there have been times when we've been able to see patients get the support they need. There have been times also, unfortunately, when individuals have had to either remortgage their house or even move into a different location, and that's sad.

Andrew Schorr:

I know we don't have an easy answer, and I should tell folks this is front page news put out by ASH in the newspaper they come out with every day. I don't have the newspaper in front of me, but it's about costs. It's a big debate. Some of you have seen the *60 minutes* program about it. My friend Dr. Kantarjian...

Greg Stephens:

Yes.

Andrew Schorr:

...who deals with CML, who is at MD Anderson. There was a *New England Journal of Medicine*, *New England Journal* article about all this stuff. So we have to figure this out in cancer as more of us are chronic cancer patients. So I wish we had an easy answer.

I will make this suggestion, as Greg mentioned, connect with a society like our friend here, the National CML Society, and go over all this. Get coached. See if there are assistance programs. They can guide you, right, Greg?

Greg Stephens:

We can guide you, point you to a variety of things. And you know one other thing, Andrew, that you mentioned, getting connected. You know we're only as strong as our weakest link, and when we're divided and scattered that diminishes our ability to make change.

Andrew Schorr:

Have a stronger voice as a group.

Greg Stephens:

That's right. And you know there's legislation. There's drug parity legislation that it's approved—been approved in over 30 states now. However, we need that legislation to be at a national level. Also there's legislation regarding price tiering. So unless we can combine our voices and address those issues, you know, we're going to continue to see these problems happen, so.

Andrew Schorr:

Greg Stephens, I want to thank you for all the work you do.

Greg Stephens:

Thank you.

Andrew Schorr:

Leadership. People may know Greg lost his mother to CML years ago, and he's been just an Energizer Bunny, if you will. He's been...

Greg Stephens:

The Energizer needs...

Andrew Schorr:

Yeah, he's leading it, but he needs you with him.

Greg Stephens:

That's right.

Andrew Schorr:

So really add your voice for patients with chronic cancer, in this case CML. He's really been a pathfinder, and we have to deal with these cost issues.

Thank you for joining us. We're on location where things are happening at the American Society of Hematology. And be sure to look for our updates and be signed up, so we can let you know whenever we post something new. With my friend Greg Stephens, Andrew Schorr. Remember, knowledge can be the best medicine of all.

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