



Patient Advocate Perspective: Stopping CML Treatment After Remission

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr in San Francisco at the American Society of Hematology meeting with my friend Jan Geissler from Munich, Germany. Some people, of course, know that Jan has been living CML with since 2001. What they may not know is that two months ago he stopped therapy as some other patients have done. That's been discussed a lot in the CML community. So first of all, how ya' doin'?

Jan Geissler:

I'm doing well, extremely well without taking therapies. It's a good life.

Andrew Schorr:

That was a big step.

Jan Geissler:

It's a big step, and I must say it's been taking me quite a while to take that decision. I mean I stopped the targeted treatment already in 2006, but I had the interferon going on for quite a while until actually about two months ago. But let's say the comfort level of just taking the drug and forget about it was quite high, and then stopping and going back to very frequent monitoring and so on is quite a step. And now I'm waiting again for results, and it's an interesting thing from the psychology side of things.

Andrew Schorr:

Oh, I'm sure. Now, you are probably one of the most plugged-in CML patients in the world, and this has been discussed. Can you take a medicine or medicines for some time, have the disease knocked out or knocked down to such a low level, what are you thinking about the whole idea of cessation generally in CML?

Jan Geissler:

Well, I think it's an important topic. Of course, I mean you can see it here at ASH. I think about nine posters or sections are actually discussing the topic of stopping treatment. And the good thing about it is those patients who have sustained deep molecular remission and have had the CML at a very minimal level. And about half of them could actually stop treatment safely and have no returning disease.

But, of course, for the other ones where it returns even though they respond well to the treatment, they've had no therapy for quite a while. And they know they need to go back to these low-grade side effects. And so they might feel even worse before than when they stopped, because in the end they said I've actually failed on stopping treatment. And so they come from a very comfortable, very safe harbor and going back into the let's same thing again. So psychologically it's not easy. And at the same time, it only works for a proportion of patients, because you need to have that deep level of response,

which probably about 20 to 30 percent of patients will ever reach. Which means stopping is not an option for about 80 percent of patients. So as much as we hope everybody can, at the moment it's something for part of the population.

Andrew Schorr:

So in your condition, whether you're able to stop or whether you're able to have a better medicine or even a combination of medicines, are you encouraged that people can live and live pretty well? Because it wasn't so many years ago when people didn't.

Jan Geissler:

No, it was very different. I mean if you look at the time when I was diagnosed the standard therapy basically meant to a certain extent that people were either dead or very morbid after having bone marrow transplant. Today, for most patients it's taking a pill a day. And with low to little to medium side effects, they can live a normal life, maybe become 80, 90 years old. This is what we hope. And there was a presentation here at ASH that actually the morbidity, the mortality due to other reasons is almost higher than dying of CML. This is good news, isn't it?

Andrew Schorr:

Sure. So there you are, so you're in a transitional state. We hope it's not transitional, that it stays the way it is. And yet for other patients continuing questions to be answered, understanding their version of the disease and what is right for them and then make the decision that they're confident about.

Jan Geissler:

Yeah, yeah. And actually making it is not easier today than it was before, because people have options. We have five approved targeted therapies at the moment. Each one has its own advantages, disadvantages, healthcare systems, reversing them all. The whole system is changing, because generics are now coming to the market with the end of the patent of imatinib. And for some that stop or I have the option to stop, some say I don't want to stop, this drug has saved my life. Why should I change something that works? Why change a winning horse? So there are a lot of questions we have, which is always a balance between co-morbidities and other side effects and feeling in the safe harbor and so on. It's an exciting time still.

Andrew Schorr:

Well, it is. But the good news is because of this man and a small band, you are not alone—and a growing band. So Jan and other board members, developed CML patient advocates, you're in how many countries now?

Jan Geissler:

We're in 68 countries now.

Andrew Schorr:

Sixty-eight countries. So wherever you may be, really, you can find information and support. Obviously, it'll be in consultation with a doctor you trust, but you're not alone. And that's a big deal.

Jan Geissler:

Yeah, it's a great network and very encouraging and great people in the network too. So I can just encourage everyone to go there.

Andrew Schorr:

What is the website again?

Jan Geissler;

cmladvocates.net.

Andrew Schorr:

cmladvocates.net. Okay, Jan, thank you for all you do. And let's pray for more and more progress in CML, whether you stay on a medicine therapy that works for you or you're able to stop. And was may your cessation become permanent and you have an ever-longer active life, okay?

Jan Geissler:

Fingers crossed.

Andrew Schorr:

Andrew Schorr on location in San Francisco with my friend Jan Geissler. Remember, knowledge can be the best medicine of all.

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