CML News From ASH: Patient Advocate Perspective

Jan Geissler
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CML Patient Advocate

Esther Schorr:
Hi there. This is Esther Schorr with Patient Power, and I'm here at ASH 2018 with many thousands of hematologists and oncologists, but I'm also here with some amazing patient advocates from all over the world. And I am standing next to one of our very favorites, Jan Geissler. And, Jan, you are such a busy guy, tell our audience who you are and what you're up to now.

Jan Geissler:
Well, my name is Jan Geissler. I've been a patient advocate for 17 years, and I've been in advocacy, numerous roles being one of the founders of the CML Advocates Network and also one of the founders of the Acute Leukemia Advocates Network, which is our newest baby. And I've also been involved in coordinating, EUPATI, the European Patients Academy, to train patients about medicines, R and D and regulatory affairs to really make them full partners in research and development and regulatory decision-making, and so on.

Esther Schorr:
And you don't sleep.

Jan Geissler:
I sleep not a lot. That's right. I don't sleep a lot.

Esther Schorr:
You don't sleep a lot. So you're at ASH. What are you hearing that's got you excited in the CML area for patients, and what are the kinds of things that you're expecting at ASH this year?

Jan Geissler:
Well, you know, CML is a disease that 17 years ago when I was diagnosed was a disastrous disease. It killed half of the people within years, and there were hardly any therapies, and today it's a disease where you have almost normal survival for the patient population, if you can access therapies and if you're treated well, which, of course, is not the case for everyone. And so, of course, what we worry about is what do we do with that percentage of patients that get progression or don't access therapies or how can we optimize therapy.

And one of the big topics we have been pioneering over the past years in CML is stopping treatment after many years of remission. And I think that's been the buzz word of the past couple of ASH conferences, to look at the trials that are going on where patients after years of deep remission can actually stop treatment. And there is quite some data also presented here at ASH where you can see that about 50 percent of people that stop treatment after years of remission relapse and

the other 50 percent doing fine and can be without therapy, which is, for example, also the case for me. So I stopped four years ago, and I'm still in good remission, so I've been fortunate. But I'm saying fortunate because we don't know why it works for some and why it doesn't work for others, and I think we're moving nearer to the goal to better understand that. And some of the presentations here at ASH are about TFR, therapy-free remission, and about the studies going on in that space.

Esther Schorr:
Is that also something that's going on in other forms of leukemia where they're looking at the ability to stop and start again as necessary? Are you familiar at all with that?

Jan Geissler:
Well, it's been discussed in a number of places, because you know you cannot take these therapies forever. They are all not smarties, so you don't know what's going to happen over many years. So I think we need to look into that. I mean, CML is an easier disease to understand because a monogenetic change into chromosomes while other diseases like melanoma or myeloma or so are much more complex, or look at AML, which is still is disaster.

So I think we are pioneering things by testing things out, and of course we hope that they are also applicable to other diseases later on by learning how we tackled it in CML. So I think that's one of the topics, of course.

There's a new drug coming up in CML. There is not so much investment into new drugs just because their therapeutic landscape is quite well set, which is called asciminib. There are some data here at the conference and of course we as patients are quite excited about that to look at how does it perform. Is it probably less toxic than the other drugs? Doesn't it have the cardiovascular side effects that many of the drugs have that we have at the moment, and so on? So that's interesting.

And another thing that's interesting here, this year quite a lot of data about pregnancy in CML, so about family planning. Because as patients, even young patients like myself, actually get old and can live a normal life of course we return back to discussions about family planning. And so we had presentations about fertility and about data being collected in an Italian registry and what kind of drugs can be taken during the first, second and third trimester and how do you manage patients that stop treatment and then relapse while they are pregnant.

And how do you handle that by balancing out the difficult decision between the risk for the mother and the risk for the baby or the unborn. And those are difficult decisions to make, and I can just tell it's extremely relevant for young patients, especially for female patients. And I've just this morning in my German forum actually had post by a lady who unfortunately lost her baby while she was pregnant and she has CML, and she stopped treatment and the CML came back. So it's a very relevant, very tough topic, I would say, for us.

Esther Schorr:
But it sounds like in addressing it within CML community that there are going to be learnings that are going to be for other areas where people are living longer and especially young, young patients with any kind of a serious diagnosis.

Jan Geissler:
Absolutely.

Esther Schorr:
They're going to have to be thinking about those things.

Jan Geissler:
Absolutely. Because, for example, one physician from the Hammersmith Hospital was presenting their MO as road map. Of course, we can hardly give, let's say, clear medical recommendations because you cannot do a randomized trial on pregnant people. But you can, let's say, by experience and by single-case reports and so on, and there are quite many in CML in the meantime, you can give recommendations how you would manage these patients or how do you handle if you detect pregnancy while having CML or how do you handle a pregnancy when CML is actually being diagnosed while you're pregnant.

So they have kind of road map of the different steps depending on, let's say, the stage of pregnancy which kind of drugs to take and which ones not and what the experience has also been on patients that against all recommendations actually took the drugs during pregnancy. And, I mean, you see a lot of things that makes you think, well, how we can be seriously managing that. So I would say that's one of the most important or interesting things for me.

There's also been an interesting post on pediatric for under-3-year-olds because CML is ultra rare for pediatric patients. So in Germany we have only 20…

Esther Schorr:
…pediatric, can you…

Jan Geissler:
…for children with CML. Of course, my disease, CML, is usually diagnosed at the age of 65 on average, but there are people—I got diagnosed at 28, but there are also teenagers and young kids which are very rarely diagnosed with CML but if they have it you need to think about they should live on for another 80 years, so how do you handle these kind of diseases. And there's been a post here which I found quite interesting, how to manage CML patients under three years of age. And that's been quite…

Esther Schorr:
…we hope you never have to deal with that, but it happens.

Jan Geissler:
Yeah, well. I think on the post we had 470—in that study 479 children with CML being monitored and 22 of them were children under three, so it's ultra rare but nevertheless extremely important.

Esther Schorr:
And we have to care about it. We have to figure out what to do.

Jan Geissler:
We have to care about it. And we need to think about how to actually apply therapies because you cannot talk about food effects and about all kinds of things that we usually, you know, our daily life with meds is just--it's clear that you don't eat if you can't eat for therapies, but how do you do that with a three-year-old which can't consent, where you can't even explain how to do that. So it's--

Esther Schorr:
It's a lot.

Jan Geissler:
It's a tough area, I would say.

Esther Schorr:
Well, but I'm glad that you and the researchers and the oncologists and hematologists are thinking about these things now and trying to make progress. So, Jan, thank you for sharing your wisdom and your enthusiasm. It's good to see you doing so well and sharing your perspective on all these things.

Jan Geissler:
And thank you for reporting from this conference, because, I must say, think about we have about 40,000 people here, and we have just a handful of advocates at this meeting. The fees are prohibitive, and if you cannot register as a media delegate, I mean, you—it's very difficult for patient advocates to get here, so it's very important that you report from all the things that we hear here at the conference and report it on Patient Power. I'm really grateful for that.

Esther Schorr:
Thank you very much. Well, we couldn't do it without you, either. This is Esther Schorr from ASH. And remember, knowledge can be the best medicine of all.

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