



Patient Power

Woman With Myelofibrosis Gets Unapproved Drug With Help of Care Team

Sandra Dillon

Myelofibrosis Patient and Advocate

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Esther Schorr:

Hi there. This is Esther Schorr with Patient Power, and Andrew and I are in San Diego at the Regenerative Medicine Conference, and in the course of listening to some of the scientists researchers here I met Sandra.

Sandra Dillon:

Hello.

Esther Schorr:

Who is an amazing survivor of myeloproliferative neoplasm, and she was telling her story to a roomful of scientists and researchers and us who are so interested in this. And, Sandra, I really think that your story—and then we're going to talk a little bit about the story of your support through all this. Can you just give our listeners a little bit of information about how this all happened?

Sandra Dillon:

Sure. I was diagnosed with myelofibrosis in 2006, and at that time it's—there wasn't a lot of information around the disease. It was pretty rare, and my doctors didn't really know why I got it or how, and there was even less treatment. And so getting that diagnosis, and I was 28 at the time, and really very healthy. I was training for a marathon. I ate very well. I took very good care of myself, and so really to get a diagnosis like that was pretty devastating. And to get a diagnosis with a disease that didn't have much in the way of treatment was just even more devastating.

Esther Schorr:

Right.

Sandra Dillon:

But luckily in the time since my diagnosis there's been this tremendous amount of advancement in research and in discovery, and part of the reason we're here today was talking with folks from (?) Cerm who funded or helped to support this advancement in research and acceleration to trials so that when—it was around 2011 I'd started getting quite a bit sicker.

Esther Schorr:

Right.

Sandra Dillon:

Because it's a progressive disease. And at that time I came here to San Diego and started to see Dr. Jamieson, and she was able to get me on a trial for a drug that—you know, it was brand new. It was just something that we didn't, we didn't have access to before.

Esther Schorr:

Right. So this was quite an incredible set of circumstances. And talk a little bit about this trial. I mean, I understand like you're the person in the trial. How did that happen?

Sandra Dillon:

Yeah, it was pretty incredible. Well, at that time the drug, it's called fedratinib, it just changed everything. I suddenly went from being very sick, exhausted and I could barely stay awake, I could barely walk up stairs. It was just exhausting. To be full of energy and revitalized and really I just felt completely healthy again in a pretty short amount of time being on this drug. So it just—it was amazing.

Esther Schorr:

Were you the only one on the trial?

Sandra Dillon:

At that time, no, no. There were a number of other folks that were getting onto fedratinib. I think I was in a stage, just started Phase II, and things were great. But then the trial halted, and suddenly I was faced with this sort of oh, no, like I needed that drug. Like you get pretty attached to something that's keeping you alive.

Esther Schorr:

So folks know, so when the trial was halted, even though you're on the drug and it was working well for you, you could not continue to take the drug. Okay. So what happened?

Sandra Dillon:

So within days I was, the drug was done, I was off of it, and amazingly—the people at UCSD and Dr. Jamieson's team are amazing, and again quite a lot of research had been done and so at the time I got onto ruxolitinib (Jakafi). It had just gotten approval, and we were optimistic, but it was, pretty quickly they realized it wasn't working, and it didn't have an effect on my disease, and my disease was slowly creeping back. My previous drug had just really pummeled my disease like really pushed it back.

Esther Schorr:

So what happened then?

Sandra Dillon:

So I did slowly start to get a little sick again, but Dr. Jamieson got me on another trial, and I did really well on that trial. It was through NS Pharma.

Esther Schorr:

So is this a separate drug, a third drug?

Sandra Dillon:

Yeah, yet another drug.

Esther Schorr:

Okay.

Sandra Dillon:

These guys just won't quit.

Esther Schorr:

No, that's a good thing.

Sandra Dillon:

So I was on that drug probably for a good two years, and then it stopped working, and my disease just kind of found a way around it, and I really started to get sick. I fell pretty, pretty steeply, so I suddenly needed to get blood transfusions and things were looking quite bad. All the while I knew, we knew there was a drug that was working for me.

Esther Schorr:

So what happened? What happened with this drug?

Sandra Dillon:

So, yeah, amazingly, even though this drug was on hold and totally unavailable, that group of doctors got together and fought to bring it back. And how do you bring a drug back? Well, you need your drug maker to make the drug. You need the FDA to let you take the drug, to approve you.

Esther Schorr:

You need patients to say I really need this drug, right?

Sandra Dillon:

Yeah. And you need a hospital, an institution that is willing to treat you with a drug that had been pulled, and that seemed pretty daunting. But the doctors came together, and they got everybody to go for it and bring this drug back, like, for me.

Esther Schorr:

Okay. And so now you're on this drug.

Sandra Dillon:

I'm back on the drug.

Esther Schorr:

And you're looking great.

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