



Patient Power

How Do You Know When It's Time to Switch MPN Therapies?

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Andrew Schorr:

So, Ann, you went many years with just aspirin, I think, and I'm not sure

Ann:

Yes, and phlebotomy.

Andrew Schorr:

And phlebotomy and then it turned out peginterferon alfa-2a (Pegasys) interferon was a good idea for you. And it's done well. So what was going on that made the switch?

Ann:

What made the switch was that my spleen was so big, I couldn't bend over to garden and, next time I saw my doctor, I said "We can't go on like this. My spleen is way too large." It was 21 centimeters under the rib, which is all the way down to the navel. And he said "I agree. Let's do something." And that was the—he left the practice the next week. So the last thing he did for me was to make sure that I was cleared to do—to use Pegasys.

Andrew Schorr:

And it's worked well.

Ann:

And it's worked great.

Andrew Schorr:

So, Dr. Heaney, let's talk about that. Is—how do you know—Jonna is on Pegasys, as well. Some people may be on aspirin, like she was, etc. How do you know when to make a switch? What are you looking for?

Dr. Heaney:

So for me, for patients with polycythemia vera, it's a balance between trying to maintain them on phlebotomy versus using something to bring the counts down. One of the—we can always reduce the hematocrit with phlebotomy but there can be a danger if patients become overly iron deficient because you need iron for other bodily processes.

So—I—usually, if patients really become iron deficient, in order to control the hematocrit, that's the time when, I think that—that we need to use some cytoreductive medicine. And, at other times, just as Ann was saying, if the spleen gets to be

too big and starts to compromise activities of daily living, then that's another time when—than just taking red blood cells out won't control that and we need to use something reduces the cell count.

Andrew Schorr:

And, Jonna, you've had concern about low iron, right? I mean, you've had some fatigue and low iron's been an issue for you, right?

Jonna:

Yes, it has. I have a lot of fatigue and I believe that the low iron is really what's causing it. So, hopefully, when my counts get under control, I might be able to get my iron back up. Pegasys—Pegasys, for me, was an interesting journey. My doctor actually wanted to start it about two years ago and I really didn't want to, just yet. And I think the main reason he wanted me to start it maybe was because I was younger progression. I believe that he was trying to maybe prevent progression and I actually traveled—I didn't really want to—I was resistant and I actually traveled to get a second opinion on starting the drug and that doctor disagree.

So I didn't start it right away and I actually waited for another year-and-a-half and, finally, my counts got to the point where I did something: my platelets were too high, my white blood cells were too high and other numbers were too high. So I still am hoping that, once my numbers get under control and I can actually add some iron—my ferritin is very, very low. It's like a three. So, I'm hoping that, when I get some iron back in my system, I will feel better.

Andrew Schorr:

I hope so, too. That sounds reasonable, Dr. Heaney?

Dr. Heaney:

It's a—iron is kind of one of the fuels for the red cell production in patients with polycythemia, so it's a—it's a delicate balance that the patients run between being iron deficient to help control the hematocrit but, as you point out, it's not just hematocrit, it's also the platelet count and the white blood cell count. We think that, when the platelet count gets above a million, that—that that increases the risk of blood clots. And we think that the white count also plays a role in—in increasing the risk of blood clots, although those data are a little bit less definitive.

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