



Andrea's Story: The Fight to Live Well, Not Just Live Longer With Myelofibrosis

Andrea
MPN Patient Advocate

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Beth Kart Probert:

Andrea, you were diagnosed almost 19 years ago. Tell us about that. Why were you diagnosed? What was going on in your world?

Andrea:

My primary care doctor said to me, "I've been noticing that your platelets are on the rise." And she showed me the chart. And she said, "I don't like it, so, I think it's a good idea for you to see a hematologist in Dallas. And I have a great guy for you." And so, I did that. And we did diagnose my condition as ET, essential thrombocytosis. In the beginning, I didn't do anything because my platelets were low. They were maybe in the 600,000. But I happened to have a physician that is very conservative.

And he said, "We're taught that we don't treat this disease until they're 1 million or higher. But I have had some really bad experiences, and I don't want you to have a stroke or anything of that sort. So I would like to treat you, even though you're at 600,000 or 700,000." So, I said fine. So I went on anagrelide (Agrylin) and did that for 10 years. And similar to Brad, I was great. I was riding my bike. I was working. I was doing everything. I didn't even know I had a disease. I'd walk into the doctor's office just like you and say I feel so—look at these people, I feel so great. They're old. I'm doing great.

So, oh, how things change. Then, we went away on vacation, and I started feeling rather fatigued after about 10 years. And I thought something is not right. So I went back to the hematologist. He took some blood tests. And he said, "I just don't like the way this looks. And you're not feeling the way you did."

"I'd like to send you to MD Anderson." He said, "I could do a bone marrow biopsy, which is the next step to diagnose this. But they're just going to do another one there. So, unless you really want two, which those who have had it know you don't, I'm going to send you there." And I first went to Dr. Kantarjian at the Leukemia Center. I don't even know that Dr. V was there or there was a specific department for MPNs, at that point. And we talked about going on a clinical trial. I was not the kind of person to sit back and just say I have an incurable disease. It's going to progress.

At that point, the life expectancy, of course, the Internet said, was three to five years, maybe seven. And that wasn't okay for me. I wanted to do something and, at least, tell myself that I had made some effort to fight this disease and live healthy, not only longer. So I have since been on four trials, depending on how you count.

And I hooked up with Dr. V. And his team, you guys are the greatest. So, for the last nine years, I've been at MD Anderson with Dr. V and his team. And we've tried different things. And I'm the same way. We talked about it before. People will say

I'm on this and I'm doing great. And I think why aren't I on this. And I talked to Dr. V about it, do some reading about it, and we go forward. Mometotinib has been my drug of choice for the last six years or so, five years if you count CYT387. And it's not working anymore, or I'm not working anymore. I don't know if it's the drug or my body.

But I'm back on transfusions. I was independent of transfusions for six years, which was great.

Again, riding my bike, feeling great, until I didn't. So, I'm back on transfusions again, and we're looking for the next step. Yesterday, I happened to come and see a stem cell transplant doctor that is on the agenda.

So, I went to see a transplant doctor yesterday, which really gave rise to many questions and a lot of thinking. And I have a lot of conversations to have with Dr. V before I take that step. But it is a step in my journey. And that's kind of where I am right now.

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