

Diana's Story: A 17-Year MPN Journey

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Diana Riley
Patient Advocate

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Andrew Schorr:

Hello and welcome to Patient Power. I'm Andrew Schorr. Diana Riley was diagnosed 17 years ago with an MPN at age 39. She's here to share her story. Diana, thanks for being with us.

Diana Riley:

Thank you for having me.

Andrew Schorr:

Diana, tell us about your journey over the past 17 years.

Diana Riley:

Well, it's been pretty uneventful. As you said, I was diagnosed 17 years ago, kind of one of those surprise things. You go to the doctor thinking you're going to go home with a good report, and you—they call you the next day and tell you to come in and have some further testing. And I, through a friend of mine who was a drug rep here in downtown Chicago at the time—I'm from northwest Indiana, little town—and anyway she did some checking she said, you know, this is the doctor that you need.

And I came to Northwestern to Dr. Winter, who I was with for many, many years and wonderful doctor and she kept me alive. And the best piece of advice that she gave me at that point was, you know, just do whatever you can to stay healthy. Live your life, and do whatever you can, exercise, eat right and be as healthy as you can in general, and then everything else will just be better.

So I've tried to do that, and when Dr. Stein—I know someone, the previous speaker was referring to Dr. Stein. When he came she referred me to him because this is his area of expertise, I have been seeing him actually less than a year. And my diagnosis was actually changed from ET to MF, which he believes it was actually MF at the beginning. So it's a little bit strange being diagnosed with an old people disease when you're in your 30s, but that's what happened, but I'm still here 17 years later and doing very well.

Andrew Schorr:

What treatments have you had over the years?

Diana Riley:

I initially was on hydroxyurea (Hydrea) just very briefly, and that was when anagrelide (Agrylin) was brand new and needed to be preapproved from my insurance, so, very briefly, I was on hydroxyurea and then on the anagrelide, or Agrylin. And shortly after I started on that I did have a little visual symptom, which I had had previous to my diagnosis, so I didn't really know that it had anything to do, but—so then I started on aspirin, and that's been kind of played dose-wise. And clopidogrel (Plavix), I'm on Plavix every day. And as of last December, I got rid of Agrylin and went on peginterferon alfa-2a (Pegasys). So I take one injection a week, and I still take my Plavix every day and one baby aspirin two times a week. And that's it.

Andrew Schorr:

Have you experienced any side effects?

Diana Riley:

I'm happy to say I have no side effects from any of my medications.

Andrew Schorr:

Your doctor is an MPN specialist, Dr. Brady Stein from Northwestern. How important was it for you to connect with Dr. Stein?

Diana Riley:

I think it was very important. Like I said, I had a wonderful doctor. Dr. Winter was great, and she had been consulting with other doctors in the course of my many years with her. But when Dr. Stein came she said, you know, this is the guy that you need. He specializes in this, he does research in it, and this is who you need to go to. So I changed over, and I'm very happy. I miss her, but I'm very happy with him.

Andrew Schorr:

How do you feel about your future? Are you hopeful?

Diana Riley:

I'm very positive about the future. You know, I'm a diabetes educator, and it's hard to keep up with all the changes in medicine, and I'm seeing that in the field of hematology also, that there are new changes, new studies new discoveries. So as of right now I am—all my genetic testing has been negative, but they think they're on to something and there will be some testing here in the fall that I can participate in, so—but I'm very positive about the future. It's been 17 years of no problems, and I'm hoping for a lot more than 17 years in the future.

Andrew Schorr:

You've had quite a journey. What would you say to someone who was just recently diagnosed with myelofibrosis?

Diana Riley:

I would say you have to be your own best advocate. You have to seek out answers on your own. You need to make sure you're going to the right doctor. Every doctor is not a good fit for everybody. You probably would need to go to a big place like Northwestern. Don't stay in your little town, because the doctor that I was initially referred to didn't even want to see me, you know, apparently had no idea of what might be going on. So you have to seek answers for yourself. And be as healthy as you can in general so that when the treatments come along you're healthy enough to be able to take part in those.

Andrew Schorr:

Diana, it's obvious you've come to terms with your diagnosis. How have you remained so positive?

Diana Riley:

Well, I think when everybody is first diagnosed—when you first find out you have a diagnosis of any kind of chronic condition, I think there's a bit of shock there. You don't know what the future is going to hold. And you know, for any kind of cancer type diagnosis of course the first thought is, I'm going to die. And—but here I am 17 years later. And I think you just have to take one day at a time, be grateful for every day. Every day is a gift. And love your family, enjoy your family and grandkids and just live each day like it's a gift.

Andrew Schorr:

Diana Riley, living well 17 years after diagnosis. Thanks for being with us. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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