



## A 7-Year Journey to ET Diagnosis: Kate's Story

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**Andrew Schorr:**

Hello. I'm Andrew Schorr, and I'm sitting here with Kate Buck, who for a number of years has been living with ET, essential thrombocythemia. She's had DVTs as well and different issues that have come up, but it took her a long time to get a diagnosis.

So let's talk about that, Kate. First of all, thanks for being with us.

**Kate Buck:**

Thanks for having me.

**Andrew Schorr:**

So, Kate, what symptoms were you having? I understand it took seven years for you to get an accurate diagnosis. What was going on?

**Kate Buck:**

It was all in the lower extremities, the legs, the feet. One day, it would be like a gout in the toe, then it would be a purple blotch on the left foot. It would go one side to the other side. You could almost watch the colors swirl.

I remember one day taking my kids to school, I was in Chicago at the time and I just—the sweat would break out.

I couldn't move one foot in front of the other. And then it would pass. I would wake up in the middle of the night, hot feet, cold feet. It really—it just—it was all down there. I did all the tests. Went through a lot of podiatrists, autoimmune specialist, saw a hematologist. He did circle—I was symptomatic about 500 platelets, and he circled it and said, "That's high."

**Andrew Schorr:**

Yeah.

**Kate Buck:**

And then let's come back and do another test. And, you know—or when you have symptoms, you know, make an appointment. So I just went through a lot. Went to a museum the next day, had a black little toe, the whole toe.

**Andrew Schorr:**

Oh, my.

**Kate Buck:**

And I went to the podiatrist, and he said you need a cardiologist, so that—then I started going down...

**Andrew Schorr:**

The cardiology route.

**Kate Buck:**

...that little vein of testing.

**Andrew Schorr:**

Wow.

**Kate Buck:**

And ultimately was referred to another doctor who was a hematologist-oncologist at another hospital, and he looked at me and just kind of raised his eye brown and was like, "Duh."

**Andrew Schorr:**

Duh. Right. But that's the thing is medicine is complicated. The symptoms can be variable. You had feet problems, so you said, I'll go to a podiatrist...

**Kate Buck:**

Mm-hmm.

**Andrew Schorr:**

...which the uninitiated would, right?

**Kate Buck:**

Yeah.

**Andrew Schorr:**

And then you're told you have this fairly rare condition you've never heard of.

**Kate Buck:**

Yes. Yes.

**Andrew Schorr:**

Okay. Now, let's talk about your treatment. So you've been on what treatments since your diagnosis?

**Kate Buck:**

Started on anagrelide (Agrylin) for the first five, six years. Then we were transferring—again, in Chicago it was February. They get snow there. We were changing from anagrelide, and he said, "Let's go to hydroxyurea (Hydrea)", and I was like, "Fine." We were shoveling snow, and the next couple of days I just started doing the dry heaves, and my daughter—I've a pretty high pain tolerance, and my daughter said, "Enough already."

Of course, my doctor was skiing, so nothing was really determined. That's where they thought it might have been a dissected aorta.

**Andrew Schorr:**

Wow.

**Kate Buck:**

But, again, it was inconclusive.

The next year, probably not my brightest moment, we were relocating from Chicago to the San Francisco area. And with all the outgassing of carpets and new paints, just getting the house ready, again I started dry heaving and said, "I can't deal with this right now," went to bed. And couple days later, the carpet was done, paint was done, continued with the getting the house ready. And then when I moved here the next year—and this was all—I should go back and say the platelet count was normal after that first episode with the snow shoveling. So said let's give the body a rest. Platelet counts were normal.

**Andrew Schorr:**

No medicine.

**Kate Buck:**

No medicine. Platelet counts were normal. When we moved here, I did research and went to Dr. Gotlib and said...

**Andrew Schorr:**

Yay.

**Kate Buck:**

..."You're my guy."

**Andrew Schorr:**

Right.

**Kate Buck:**

He was fine with as long as the platelets were normal but again started dry heaving.

**Andrew Schorr:**

You've had your journey.

**Kate Buck:**

And we then—it was normal, platelet counts were normal...

**Andrew Schorr:**

Right.

**Kate Buck:**

...but I had a 7 millimeter in the aorta.

**Andrew Schorr:**

Clot.

**Kate Buck:**

Clot.

**Andrew Schorr:**

Right. Okay. So that's your issue, and we—people have to be mindful of that, their situation with these blood disorders.

So what would you say to somebody who's diagnosed with ET? I mean or—or even some of these rare symptoms for investigating it. But if they're told they have ET, this rare condition, sounds like get a knowledgeable doctor.

**Kate Buck:**

Very much. Find somebody that knows what they're talking about. The seven-year journey I had, I won't say consistent. It was off-and-on because you get very frustrated going to these doctors and being referred to, but I was persistent. And it may have taken me seven years, but you have to be persistent. You have to go through every avenue.

**Andrew Schorr:**

And then get to a knowledgeable doctor.

**Kate Buck:**

And then—yes. And now, well, this was kind of in the Dark Ages, but there is the Internet. You can use that as a source. But find somebody that knows what they're doing, and I've been very happy with Dr. Gotlib because he's somebody that is intimate with what I have.

**Andrew Schorr:**

Right. And how are you doing?

**Kate Buck:**

I'm doing great. You know, no problems with energy. Again, maybe it's that stubborn side, but...

**Andrew Schorr:**

Okay, Kate. Well, I'm so glad you're doing well. I'm glad you got the right treatments now.

**Kate Buck:**

...be persistent.

**Andrew Schorr:**

Being monitored, be persistent, and the right doctor. Thank you for being with us.

**Kate Buck:**

Thank you.

**Andrew Schorr:**

Okay. Let's not have a 7-year journey to get the right diagnosis or then to get to the right doctor. Find an MPN specialist so you can get brought to bear the latest treatments and the treatment that's right for you.

I'm Andrew Schorr. Remember, knowledge can be the best medicine of all.

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