



Myeloma Patient Perspective: Making the Decision to Join a Clinical Trial

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Cherie Rineker:

So what's a myeloma clinical trial like? The experiences are probably as vast as the amount of patients that are in it. Matt, allow me to start with you. What made you decide to join a trial, and how did your experiences compare to the actual expectations that you had?

Matt Williams:

Gosh, with my most recent trial I was at the end of the road. It was the last house on the block, so I was eager to get in and did everything I could to do that. I was turned down all over the place. I was on the list in several places including China, and I was told that I only had a couple of months to live and that I probably wouldn't--there was a--I had an allotransplant so I was being turned down because of that.

And then Seattle Cancer Care Alliance came up with a study that I heard about just through word of mouth. Although I was a patient there I was not aware of it. Somebody told me on social media about it, and I got my name on the list. And my doctor told me I wouldn't make it, that it wasn't going to open in time for me, and he was kind enough on his own time to do some searching for me and found the City of Hope trial that targeted my 17p deletion problem.

And so I was willing and eager and trying to get in everywhere and was continually disappointed being turned down, and I thought it was going to happen again there for sure. And I was lucky, there was a doctor, the Dr. Green there was--opened it up a little bit. There was many reasons for him to exclude me, but somehow I just squeaked in there, and my story is very similar to yours. Shortly after, in 28 days, I had no sign of myeloma in my marrow or my blood.

There was a little bit left in my PET scan, but I just got back last week from Seattle and there's zero sign of myeloma now after my 90-day test. So I'm just so grateful for clinical trials and to be able to finally get into the CAR-T trial.

Cherie Rineker:

Yes, Matt. We've gone this journey together, and I'm so, so thrilled to hear about your results from last week. Brian, can you tell us about why you decided to join the trial?

Brian Helstein:

Seriously, I really have spent my entire working life—I'm getting ready to retire, and I've spent 50 years in higher ed. I really, really had no clue at the time of diagnosis life expectancy or anything along those lines, and I figured, you know, that I was going to learn how to deal with this, that or the other infirmity the treatment was going to cause, and other people needed to know how to do that and do it better. They needed to learn from my experience. It wasn't—it just wasn't something I was prepared to take with me.

And I must say I'm somewhat rebellious about things. I have a dermatologist at this point who does not like me to go running out in the sunlight without a hat, without a long-sleeved shirt. If he had his way, I would also have ski mask and tights on. No exposure to sunlight, and I have been known to go for a long run in my running shorts and shoes.

This was not going into a clinical trial where I was going to be told you're going to take these drugs on this day, you're going to show up at such and such a time on that day. I knew that I was going to have to be disciplined, and I was going to have to follow exactly the protocol of the trial if it was going to be of any benefit to other people. So I made that compromise. I'll go running without a shirt once a month or whatever, and I will be at the doctor's office at, you know, 10:15 if that's the time I've been summoned for.

I don't know any other way to put it. It was a matter of being disciplined so I could share so that others could benefit from this.

Cherie Rineker:

Very good reason. Very good reason, Brian. Thank you for sharing. Eric, why did you decide to join a trial?

Eric Wolf:

Yeah, I think in some respects they are easy, right? So the one that I did having to do with—what is it, the shingles trial, it was there, it was offered to me. It didn't require much of me but calling in and reporting once a month on what—if I experienced anything. It was really easy, and so in some sense there's those types of clinical trials that are just sort of tag-ones to what we're already doing. Same thing with the extra marrow that was collected to do my gene sequencing. That was not really a big deal.

But like yourself and Matt, there are other clinical trials that we seek out on our own part, because we need those to manage our disease, and that was the case with the other two trials I've been on. You know, the one I'm on now is because, as much as we don't like to admit it, our options are limited, and so this is a trial that's there and available and the timing lines up, and so you do it.

Cherie Rineker:

Excellent. So anybody else besides Matt and I has had to travel long distances for their trials? And then Barb, I'd like to ask you the same question as well, so maybe you can answer that.

Barb Hansen:

Well, I certainly didn't have to travel. I'm right here in the Denver area. I think what really helped me make the decision, and my family helped also, is that I really felt confident with this new doctor I was seeing. I had seen someone for five months, a hematologist-oncologist who was not a specialist in multiple myeloma, and then after attending a stem cell seminar and this doc answering five questions in like five minutes I just felt very confident with him. So I started, I transferred my records and just felt very confident with my healthcare team, and it was his recommendation.

Also, I have kind of a science background and my son does cancer research, and I know that the new science isn't going to happen without clinical trials. I'm a real advocate for clinical trials and did—I volunteered for Colorado Cancer Research Program, which coordinates all the trials. So it's been a rewarding experience.

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