



Will I Feel Like a Guinea Pig? A Four-Time Clinical Trial Participant Shares Her Experience

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Andrew Schorr:

Reina, so, we talked about the cultural differences of people being in trials. We talked about the pride people may have in asking for assistance, the fear people have maybe participating in trials. You still have a—not now. I mean, you're doing so well, and you've been through trials, and it's worked out well. But there must have been some bumps along the way. Were there any misgivings at different times? And if so, how did you overcome it?

Reina Weiner:

Oh, yeah. Well, there were definitely misgivings, I am sure. The first trial was when I asked the doctor if there's something going on at the NCI. And there was no misgivings about that because that was a very observational trial. The second trial was much more progressive and I felt kind of a little uncertain about it, and so I asked the researcher at this well-known institution if I should participate because the trial, I should back up a little bit, that was for either smoldering myeloma patients or active disease patients.

At the time I was smoldering, and most physicians didn't believe that that was a good idea to treat smoldering and wait until it became active. So, I asked this one researcher and he said absolutely, not, do not participate in the trial. And then I called someone else also from a very respected institution where I had been, and he said well, if you join that trial you'll be crossing the Rubicon, which I didn't even know what the Rubicon was at the time. I had to go look it up.

But, basically, once you start treatment, you kind of go on that journey and there's no way to step off. But then I thought about it, I thought about it, thought about it, and finally I decided to trust myself because I had been to the NCI. I felt very safe there. And I decided to move ahead with it.

So, yes, I had plenty of misgivings about that. The other trials, not really because that trial changed my life and it gave me a very reasonable complete response. And the other ones, like I said, they just kinda fell in with the collecting a good amount of stem cells for a transplant and so forth.

Andrew Schorr:

I wanna talk about family issues. So, the decision to be in a trial affects the family, whether it's somebody's driving you to the doctor, somebody's taking off work, their worry, how they feel about trials, their own view of it, family logistics, costs, et cetera. We've talked about that. So, you wrote this blog about people questioning your husband, I guess, was your wife gonna be in a trial? So, how did you overcome that, whether if not with your husband, just with your community that you weren't like crazy?

Reina Weiner:

Well, they already know I'm crazy, so that's a total aside. But, really, trying to educate people about the misinformation about trials; say, look, I will never be a guinea pig because that's not what trials are about. And it's very well controlled, and there's a lot of data that follows you. The care that I got was excellent.

And I try to dispel, like I said, a lot of the myths; that you signed consent form, which clearly explains what the trial is about, what your commitment to it is, and you can also drop out for any reason. There was hope that you don't because they would like to have some results that then will lead into future treatments for patients. But you can drop out, so, really, taking that opportunity to educate people about what a clinical trial is like and that there are no guinea pigs.

Andrew Schorr:

I wanna just—oh, yes, please, Dana.

Dana Dornsife:

Yeah, if I could just offer something in that regard. For people who haven't gone down this path, the journey with cancer, having a cancer diagnosis is not like other chronic diseases, right, like diabetes, for instance, that you can typically control with insulin or whatever, right? For a cancer patient who has failed standard of care, who's gone through maybe second- or third-line treatment options, but still has progressive disease, that patient will die if they don't do something, right?

And so, clinical trials offer tomorrow cures today in some instances, right, and we don't always have positive results in clinical trials. But for a patient who's at that crossroad where their doctor has delivered those words, "You need to get your affairs in order," right, it's not a matter of am I crazy if I participate in a clinical trial? What it is a matter of is do I wanna live? And if so, what clinical trial can I participate in? It's a very different decision tree.

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