



# A Step One in Trial Participation: How Can Patients Learn About New Trials?

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**Andrew Schorr:**  
So, Reina, you had been in the pharmaceutical industry.

**Reina Weiner:**  
Yes, I had.

**Andrew Schorr:**  
So, you knew about drug development, and you understood about clinical trials. So, I'm willing to bet you were pretty proactive. People who weren't in the field, they don't know from clinical trials, and maybe they'd been worried about it. They've worried would they be experimented on, would they be a number and not name, would they get quality care. But you were probably, I have a feeling, pretty proactive. And you write about that. I know you have a book as well. So, is that step one for people to speak up for themselves?

**Reina Weiner:**  
It is step one; absolutely, step one. And what I found is, first of all, people don't know about trials. And if you go to a small community practice where they're very busy, they don't have the time, they don't have the staff to really educate patients about trials, the best, best step for patients to take is to ask, "Is there a clinical trial that might be appropriate for me?" That's huge.

Even when I went to a very well respected hospital, and there was a researcher who was following me as I had smoldering myeloma and the numbers kept going up and up and up. I said is there—because I was living close to the NCI—is there a trial that would be appropriate to me at the NCI. And he said just a minute, turned around, went to his computer, found the trial and that's how I got in.

**Andrew Schorr:**  
But it wasn't at where you were receiving care or being monitored at that time. It was somewhere else.

**Reina Weiner:**

It was not. It was at somewhere else.

**Andrew Schorr:**

Okay. Dana, is one of the obstacles, not just financial, or maybe it's even the business of cancer where if an oncology practice that you're going to that's maybe close to home is not doing the trial, maybe it's not even in their financial interests to tell you. I mean, is there an awareness issue, do you feel?

**Dana Dornsife:**

There's a huge awareness issue there, Andrew. And it all starts with knowledge is power, right, so I completely agree with Reina's comment about one of the first questions you need to ask is, is there a clinical trial out there for me, because many doctors who are in community environments don't offer that information. It's not what they do every day. They're there to administer standard of care. Only 6 percent of doctors actually engage in conversation with their patients about clinical trials, and that's usually the 6 percent who are associated with research universities, right?

So, knowledge is power. If the patient doesn't know about a clinical trial, they're never going to participate. But once you find out and once you've identified an opportunity, the second biggest hurdle is that out-of-pocket expenses associated because most patients have been dealing with their disease for a longer period of time, and they're basically broken in every way: physically, emotionally, spiritually, and, sadly, financially.

So, patients start to make decisions about the outcome of their care based on the size of their checkbook, and not focused on what's best for them. And so, Lazarex eliminates that financial barrier as well to help patients say, "Yes, I can participate," and we can get them where they need to be when they need to be there.

And that's just the tip of the iceberg, Andrew, because there are many other barriers that exist; socioeconomic barriers, language, culture, historical barriers. And we are tackling all of those barriers one at a time. But really, the biggest two barriers are knowledge and financial.

**Andrew Schorr:**

Right. And you mentioned about the historical barriers. Some people know about the Tuskegee experiments with African-American people, so in the African-American community, there still is a distrust among some people. Yet if you think about it from the FDA's point of view where a company that's developing a drug, or the NIH, they say okay, how does it work on broader populations or different ethnic groups or different ages or genders, et cetera?

They want to understand that data, and so not just having a number of people participating in the trial, but having it reach people who are in different situations, if you will. And so...

**Reina Weiner:**

...and if I may—oh, I'm sorry.

**Andrew Schorr:**

Reina, please, go ahead.

**Reina Weiner:**

Well, if I may say that because people don't know about it and the trials, the best trials, are trials with a variety of patients, but they do try to accrue populations who are certain ages, certain genders, ethnic groups, whatever they can get. And only 3 to 5 percent of patients participate, cancer patients, participate in clinical trials, and so much is lost if people don't participate.

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