



PARTICIPATING IN RESEARCH: ENGAGING IN CLINICAL TRIALS AS A PATIENT

With: Patty Spears, Bob Lipman, and Dr. Angela Smith



Questions and Answers

What is “accrual”?

Dr. Angela Smith: I'll take that. Accrual is just a word that basically means that each study has usually a target number of patients that they want to enroll, let's say, well for the CISTO study, as an example is 900. Accrual is just the word that means that, how many patients are basically enrolling in the study. That's what accrual is.

When advocates are required to attend meetings in person, how are the associated financial expenses paid in general?

Patty Spears: I can answer that for the Alliance for Clinical Trials in Oncology. The patient advocates have funding to attend the two meetings a year. Yeah, we think it's not right not to fund them to come and they go to every in-person meeting.

Bob Lipman: As a patient, I have not paid to attend any of the in-person meetings. Through BCAN and the funding from PCORI, they have covered all of my travel costs.

Related to the CISTO trial. Is it too late for a patient to get involved in the CISTO study or to be on the advisory board?

Dr. Angela Smith: Yeah, that's a great question. Well, right now we have the advisory board set. Of course, we have a certain number because we want to be able to, well, go into glass question, to be able to fund them to attend the meetings, to participate. At this point, we do have that setup. However, there are a lot of other studies that we are still looking for individuals who

are interested. After this, please feel free to either contact Stephanie, BCAN. Let me know, if you're interested in participating in something similar, because they have other things in the non-muscle invasive bladder cancer space and other spaces as well for bladder cancer, that very well might be something too that has to be of interest to you. I'd be happy to search up with that.

Bob Lipman: Right. From the patient perspective, I think definitely contact BCAN. Just get dialed into the whole process so that you're recognized as someone who wants to participate in these efforts.

How do you get involved?

Patty Spears: Yeah. I mean myself, yeah. I always tell people to start local in your own community, if there are opportunities. When I got involved, I started local. I am in an area where there's lots of institutions like UNC and Duke, so there were opportunities, but definitely go to things locally, talk to people locally and network locally, and they'll be also involved in national organizations as well.

Bob Lipman: Also from patient perspective, if you can attend the Bladder Cancer Leadership Summit, that's usually in the fall every year in different locations. It's been local to the Washington DC area. Once it was out in Houston. That's an excellent opportunity to meet some of the patient research advocates and to meet people like Angie Smith.

Patty Spears: Wonderful. I guess, I would just say stay tuned because if you can't start local for whatever reason, you don't know where to begin, BCAN is the perfect place because we can connect you with either local individuals who are interested or we can provide you with all the different options and I say stay tuned because we're hoping to revamp the website so that there is a way to do that more seamlessly online. In the interim, simply contacting BCAN will be perfect way to get the ball rolling.

Dr. Angela Smith: Yeah. I. Again, no matter who you are, someone who is just brand new to this concept or season, we really would love to have you involved. I know there's something to contribute from everyone and by working together, I really do think we can elevate research in bladder cancer to a completely new level. That means a great deal for me. I know it means a great deal for my patients. I'm sure it means a great deal for everyone who either participated tonight, or listened to this webinar. Thank you again for your time and your attention. I look forward to hopefully meeting all of you at some point.

This webinar was funded through the Patient-Centered Outcomes Research Institute grant for the PEER Integration and Scaling Methods (PRISM) Project.