

Myth busting Clinical Trials as Treatment

- I have to go to a big research hospital to get access to a clinical trial.
- I'll be getting a "sugar pill". I don't want to be a guinea pig.
- Clinical trials are for when I run out options.
- Clinical trials use outrageous or unapproved treatments.
- Once I sign up, I have to stay on the trial till the end.
- Costs are all covered. I won't have to even provide my insurance information.
- The cost of being on a clinical trial will be very high.
 - Is genetic testing required to be in a trial? Who pays for that?



Stephanie Chisolm:

Another myth that we have with clinical trials is that all costs are covered and I don't even have to provide my insurance information. But that's not always the case, right? Sometimes you have to give your insurance information to cover some of the costs and are all insurers covering the costs of being on a clinical trial? Do you know this information Dr. Shore and Dr. O'Donnell? You probably have a team of people that help patients understand it better, but what's the general consensus behind that?

Dr. Shore:

Well, I think this is an extremely important point. Sometimes all costs actually are completely covered, but not always. One of the things, depending upon where you are, healthcare in the United States is very expensive. These approved agents that Peter and I and BCAN have been involved with, once they get approved by the FDA and they come to market they're not inexpensive and they cost a lot of money. If you're a Medicare patient and you don't have good secondary insurance or you're a commercial patient and you have a high copay or a high deductible or if you don't have insurance, you're a hard working person and you just never got insurance, the cost of healthcare can be astronomical.

Where I practice in the coast of South Carolina, it's not as affluent as other parts of the country. When I'm able to get a patient into a study where all or a significant amount of their healthcare is covered and, by the way, doing that you're even saving the healthcare system because these are typically covered by grants and/or private industry sponsors so we're kind of doing some benefit to the healthcare system. Most importantly, to me, is I see so many patients who just get really, have the economic toxicity of trying to pay for their healthcare. This is where a research study, a clinical trial, is a bit of a godsend, frankly.

Stephanie Chisolm:

Excellent. These are great. Kevin and Bob, you didn't have any issues with helping in terms of being part of the clinical trial where you had to have a huge cash outlay or anything like that? Things were

generally covered and you had people that you could speak to on the clinical trial team to help out with any questions about covering those costs, right?

Patient Advocate Bob W.:

Absolutely.

Patient Advocate Kevin W.:

Yes.

Patient Advocate Bob W.:

From that standpoint mine cost didn't cost me anything. I have a good supplemental insurance through my Medicare so I am in good shape financially as far as medical costs are concerned and I have been really fortunate to have Dr. Shore. I had some real good support nurses who have worked with me, outstanding people. I am so fortunate to be around that group. And like you said, I feel like, hey, I'm going to live another day. Yeah.

Stephanie Chisolm:

A lot of drugs that are being used now in bladder cancer are really targeting specific nuances within somebody's tumor genome, in their genetic profile, so a lot of these trials are requiring genetic testing. Not too long ago patients had to cover the cost of having genetic testing. It wasn't necessarily always offered in a doctor's office. Is that something that's being covered more and is it often times covered in a clinical trial to find out if you're the right person to be testing a particular drug that's targeting a mutation? Is that something that's generally covered in the cost of doing a clinical trial?

Dr. O'Donnell:

I'll speak up here. I know I saw Kevin was trying to say something there as well, so maybe we'll give him a chance next. Regarding costs, I tell my patients, "The costs of doing a clinical trial should be nothing additional to what you would pay for getting regular standard of care," and that's actually required in the consent. Anything that would be billed normally to your insurance, like the doctors' visits, the regular labs, regular CAT scans that might be done during the course of a clinical trial, those things that are considered part of care that you would be doing, even if you weren't in the trial, will be billed to your insurance. Anything additional that the study is requiring the study would pay for, including the cost of the experimental drugs, including the cost of a genetic test if it's required in order to get into that trial. That's the general rule of thumb about how these costs work. Kevin, you and I talked a little bit about that when you were thinking about your trials initially. Do you want to comment?

Patient Advocate Kevin W.:

Yeah, I mean, that was eight years ago and at the time you were heavily suggesting that I get it because it would help me figure out what treatment, really available, not just trials, but treatments that were available for me. At the time I think it was \$5,000 or \$6,000 and we went ahead and did it. I think we were, as you had told me later, we were kind of on the cusp of this kind of changing winds and I never got billed from the genetic testing company. Somebody paid for it and I'm assuming it was the trial, the drug company. I'm not sure. My cancer was progressing so quickly at the time that I got the surgery and saw you that I'm not sure if we didn't get the genetic test that we would have picked the right thing quickly enough. I'm a big fan of genetic testing and any time anyone comes to me that has cancer that's

the first thing I ask them, "Have you been genetically tested so you know what you're dealing with. Is your doctor suggesting that? I think that's a good idea. Talk to him or her about it."

Stephanie Chisolm:

That's one of the most exciting things about the whole field of bladder cancer is it's becoming very personal and this genetic testing is being examined on so many different levels. As we mentioned earlier, it's an embarrassment of riches. We have lots of clinical trials and patients don't always get involved in them because they don't see that there's an opportunity for them to use that as a treatment option. I do encourage people to talk to their doctors about the clinical trials.

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