



### **Stephanie Chisolm:**

The next question I had, really, were there any particular things that you, Kevin or Bob, really kind of put through your own mental test about, "Well, why should I do this clinical trial?" Or are there any common questions that you, as researchers, get that you think, "Patients should ask these questions. These are good questions?" We'll start with the patients first. Kevin, was there anything that was going on in your mind that you think, **"Well, I wish I had asked this question before I got involved in the trial?"**

### **Patient Advocate Kevin W.:**

I can't recall anything like that. I'm fairly inquisitive and if you've met my wife you'd understand that she's very inquisitive. Dr. O'Donnell's smiling. One of the things that I would counsel everyone here, when I got diagnosed with cancer my mental faculties were weighed on pretty heavily, and I think when you're entering something like this and making this kind of decision it's very important to have someone with you who's not sick, who you trust, who knows you, who knows what's important to you, who knows what questions to answer and just let them go. I was a little bit of an observer for a lot of this until I got my mental faculties back. But I think my wife did an excellent job of asking all the questions so we could understand what it was.

Did we understand what it was when we started it? No. We didn't go to medical school for 16 years or whatever. But if you have a conversation with your doctor you ask questions, and like Dr. Shore said, if they won't answer your questions find another doctor. But if they'll answer your questions, engage with you, you get comfortable with the doctor, then you start to feel the doctor's got your best interests at heart and when you feel your doctor has your best interests at heart I think it calms you down a little bit and helps you make good rational decisions.

### **Stephanie Chisolm:**

How about you, Bob?

### **Patient Advocate Bob W.:**

I don't think that I can really add too much. I agree with what's been said. I had experience when I came to Dr. Shore, I had experience with cancer before some years ago. I had prostate cancer. So I had some experience with what went on and I was also fortunate to have a good bunch of medical people that were involved with me in that cancer. I had good experience there so I came with good experience about this. My only question was, really, "Am I going to make it through this? What should I do? How should I approach this?" It wasn't so much of what I should do to this or that, but I trust the physician that he knows what he's talking about. My questions are usually very basic questions. No, I don't think I have anything that really stands out.

### **Stephanie Chisolm:**

So, doctors, I think that you are perfect examples of the kind of care and research oriented clinicians that are doing this work because you have very inquisitive minds, you want to know, and you want to make this better. Is there one common question that you think every patient should ask a research team when they're considering being in a clinical trial? Have you gotten one of those perfect questions like, "Gosh, that's a great question. Everybody should ask that?"

### **Patient Advocate Bob W.:**

Well, I think your question might be, "How is this going to affect the care that I would get otherwise?" Because Dr. Shore said to me right up front, "I'm going to take care of you." And I took that to mean that regardless of what's going on in this test I come first and I think that... The other doctor's kind of mentioned that in his conversation there, that the patient comes first instead of the trial.

### **Stephanie Chisolm:**

That's a good question. Right. Okay. So, Dr. Shore, do you have one perfect question that you've been asked that you think everybody should ask?

### **Dr. Shore:**

I think I would say to... Here's one thing I say to all of my colleagues who do research is you want to have as many studies so that if you're really dedicated to treating bladder cancer that you have enough of a spectrum covering all of the different areas, like you were talking about before Stephanie, the non-muscle invasive, to the muscle invasive, to the advanced, so that you have a potential study for every bladder cancer patient. That, to me, is when you get to a level of excellence. Not everybody's there in the beginning, but that's a really great place to be so that every patient who comes in as a trial patient until proven otherwise. I firmly believe in that because that's how we'll advance healthcare.

I guess the question that I would ask from a patient standpoint is say, "Doctor, if you're doing clinical studies, tell me what your experience is, what your team's experience is with this study because I want to make sure that I'm in good hands."

### **Stephanie Chisolm:**

Okay, great. Dr. O'Donnell, do you have anything to add to that?

### **Dr. O'Donnell:**

Yeah I'll say... You asked what the most important question to ask is, I actually think the most important question to ask is asking your doctor, "Do you have clinical trials?" Or, "Should I be thinking about a

clinical trial at this point in my care?" Because while Dr. Shore and I do this all the time and every day, not every oncologist is thinking about clinical trials all the time so it sometimes is the patient that needs to speak up and say to their doctor, "Doc, should I be thinking about clinical trials?" Or, "What can you tell me about clinical trial options?" You'd be amazed, if you ask that question as a patient, how your doctor might respond. They might open all these doors to them realizing, "Wow, this patient wants to know about some of the emerging treatments, the latest treatments," and it leads to a whole conversation of them mentioning to you the things that are going on or sending you to a doc that can answer that question better. Whereas you might have been just restricted to some of the standard treatments if you didn't speak up.

### **Stephanie Chisolm:**

Great, inquiring minds want to know and you don't know what options are there, what doors you could open, unless you ask. I think that's a really important question to ask.

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