

Presented by:



Rick Bangs is a MBA, PMP; and he's a bladder and prostate cancer survivor. He's worked as a patient advocate in a variety of roles including research advocacy, government lobbying, educational support, support groups, one-on-one support, and fundraising. Rick has long been a friend of the Bladder Cancer Advocacy Network. As a research advocate, Rick serves as a member of the National Cancer Institute Council on Research Advocates as a co-chair of the NCI Patient Advocate Steering Committee. He is one of two NCI Genitourinary Scientific Steering Committee patient advocates and one of the three NCI Cancer Care Delivery Scientific Steering Committee patient advocates. Rick is the Chair of the SWOG Patient Advocate Committee, a member of the SWOG Executive Advisory Committee, and Committee Chair for the SWOG Bladder Cancer Patient Advocate Group.

Rick: What I'm going to do is I'm going to give you a very brief version of my story. You've heard a lot of my story in the intro, but I want to give you a little more detail. I want to talk about the kind of work that I do, with people like Dr. Singh and Dr. Svatek, which is called research advocacy. It's a specific kind of patient advocacy. Give you a quick overview of my perspective on what's new in non-muscle invasive bladder cancer, and then we'll move into the questions and answers.

Okay, so you heard some of the things that I've worked on. Just as background, I was diagnosed in September of 2006. I was diagnosed with Stage 2, or what we call muscle invasive bladder cancer. It was high-grade, not surprisingly. As you might expect, I had a radical cystectomy; and they also removed my prostate, because that's normal with a male have a radical cystectomy. For those of you who are interested, I chose a neobladder. I would make that choice again, but I would also suggest to you that the satisfaction levels are similar no matter what the version you choose. My choice was right for me, but you might make a different choice in your situation.

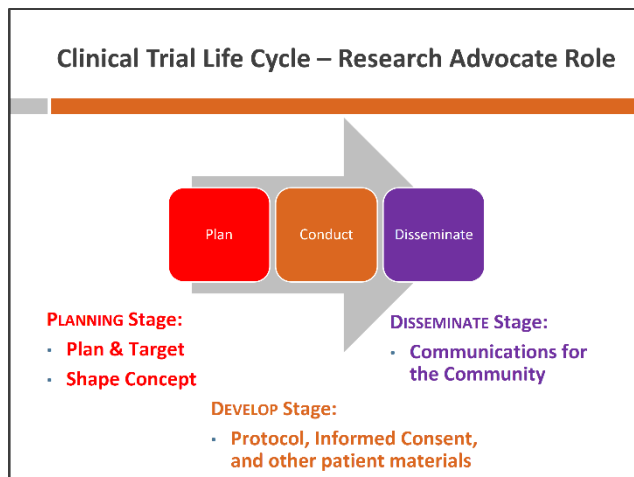


I sought opportunities to give back after my diagnosis. One of the first places I reached out to after I discovered them, was BCAN. The Bladder Cancer Advocacy Network has been a large part of who I am

and what I've become in this space. I've spent a lot of time working on various projects, including some patient tips, the clinical trials dashboard, which Dr. Singh mentioned, some articles on bladder cancer patient advocacy, and I've also participated in the leadership summit with the patient advocates. I do work with SWOG, which is one of the National Cancer Institute's virtual teams, where we bring folks together, like Dr. Svatek and Dr. Singh, from various institutions. We define, design, and deliver clinical trials.

I also work with the National Cancer Institute on the Genitourinary Steering Committee. My tenure in that role is over at the end of this month, so if anybody is interested in that kind of role, please reach out to me. I also have done some work with the National Comprehensive Cancer Network, which is one of the groups, and there is more than one; but it's one of the groups that defines the standard of care, which is the care that patients would normally get for their bladder cancer diagnosis.

This is a very simple overview of the work that I would do, with Dr. Singh and Dr. Svatek as examples, on a clinical trial. We divided the clinical trial into three stages or three stages in a life cycle. We start with planning the clinical trial. Then, we're actually conducting the clinical trial, and then we do something called disseminate, which has to do with getting the information out.



During the planning stage, we would work on planning which particular target we want to get, what the particular disease site that we want to get. Is it muscle invasive or non-muscle invasive? Is it surgery, or is it a drug, or is it some combination of that? Is radiation therapy involved? All those kinds of questions would be defined during the planning and target. Then, we shape that concept. We work through some of the details, but not at a low-level of detail; because we want to get funding approval before we're going to move into that stage.

That stage would be called the conduct stage. During that, we are actually developing the protocol. Think of the protocol as the very elaborate and detailed recipe for that clinical trial. Incredibly detailed documentation that thinks about all of the details around: Who can participate in this clinical trial? What are the treatments they're getting? What are the ramifications of those treatments? What are the side effects? Everything about the clinical trial is there. Also, would work with the researchers on an informed consent; because if you participate in a clinical trial, you will fill out and complete an informed consent. We want patients to absolutely understand what it is that they are signing up for when they participate in a clinical trial. There may be some other patient materials or communications that we would work on.

After the clinical trial is completed, then we would work on disseminating the information. We would think about what kind of communications are appropriate to get the word out on what the results are, get the word out to the community.

All right, I wanted to just give you a perspective. I've been working in this space since 2009. When I started, I would say that the set of bladder cancer clinical trials was fairly meager, was not as rich as the trials that have been mentioned on this call. There's a lot of exciting work being done in bladder cancer in general.

Specific to non-muscle invasive bladder cancer, there is increasing interest by the pharmaceutical companies. When they have interest, that means we get drugs as a result. Some of the drugs are coming from the muscle invasive space, but others would be specific to non-muscle invasive. There's more attention on bladder preservation, which includes radiation therapy in many cases. That was not the case when I started out. There was some radiation therapy and bladder preservation happening, but it was much more unusual than it is today. We've made a lot of progress in that space, and there's a lot of exciting work being done in that space, today.

What's New In Non-Muscle Invasive Bladder Cancer?

- Increasing interest by pharmaceutical companies, leading to new drugs
- More attention on bladder-preservation and radiation therapy in combination with other therapies
- Significant shortages in supply with BCG in the US in the past several year impacting patient treatment and outcomes

The third thing I want to point out which is important, and Dr. Svatek talked about the SWOG trial that he's leading on BCG. We have these important science questions that we need to answer, but we also have a challenge in terms of our supply of BCG. Some of you may be aware, but if you're not, let me make you aware of that over the last several years, we've had two large shortages in BCG. We had some manufacturing issues, and so coming up with an alternative BCG supply is critical. That's one of the important things, in addition to all the scientific things that we're doing; but that's one of the important outcomes that we're hoping for from the trial that Dr. Svatek mentioned to you.

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