



PARTICIPATING IN RESEARCH: ENGAGING IN GRANT REVIEW

With: Drs. Donna Kimbark and John Gore, and Patient Advocates: Bill Russell and Ralph Ullman.

Overview of Research Engagement

Bill Russell:

My name is Bill Russell and I'll share one personal thing with you. Next week, on the 30th of this month, I will be celebrating my 10th year as a bladder cancer survivor. The only reason I throw that in here is in the event that some of you participating in this webinar this evening aren't quite that far along in your journey. I wanted to offer it up as a word of encouragement. We hear a lot of things about five year survival rate. I like to speak in terms of 10, 15, 20 years. So anyway, I just thought I'd throw that out there. I am so excited to be here tonight and certainly honored to be serving in the capacity as moderator for this event. Trust me, we're going to have a great evening as we have three very dedicated and accomplished speakers lined up.

Now this evening's webinar will be our third and final webinar in our BCAN Participating in Research Webinar series. Our first webinar was in February and was entitled, Engaging in Clinical Design as a Patient. And that featured Bob Lipman as a patient advocate. That webinar dealt with the patient advocates engaging into clinical trial design process. Then we have our second webinar, which was in April, and was entitled, Engaging with "Pharma" as a Patient. And that featured Nancy Lindsey and Karen Sachse, which both are patients and advocates. This webinar gave an overview of the relationship between say, patient advocates and the pharmaceutical companies to make sure the patient's voice was being heard. Now this evening's third and final webinar in this series is entitled, Patient Engagement in Grant Reviews. In our discussion, hopefully we'll explain what takes place when patients participate in the grant review process.

Now, I'm assuming that some of you out there are patients and or are caregivers or perhaps you've lost a loved one to this horrific disease. As a patient or an advocate, we each have our story. And that starts with say, symptoms, goes to diagnosis, treatment options, ultimate lead to our actual treatment plans. It's somewhere during this time that our stories become real experiences. But while you're going through that process, we meet other people dealing with bladder cancer, whether it's say, maybe on the BCAN online discussion forum. Over the years, I've met hundreds of people on there. And maybe it's

been in the treatment waiting rooms, you've met a fellow patient, or maybe a family member of a patient, or it could be during our annual fundraising walk rather, in March.

Bill Russell:

But we meet the people, and we have a tendency to share stories with each other. And the funny thing I found is that, while we're sharing the stories, a lot of times are not alike at all. They're very much different. There's so many different types of bladder cancer, high grade, low grade, invasive, non-invasive, that it goes through the muscle or, all this stuff. But, it's important to share with each other and it gives us the opportunity to encourage each other. It's great to encourage someone and it's great to be encouraged. So that's good. And that's a personal advocacy, then we do advocacy in our communities as well. But as we get along, I have found anyway, as we get more involved with advocacy, there's so much more impeding cancer than having conversations.

It became apparent to me that at a point, if you want to make a difference in the big picture, you need to get involved in the process. And what I'm talking about within the process is, like in our first webinar with a clinical trial design, or maybe with a Big Pharma, maybe you are a good spokesman for your point of view and would do well in, say, representing the bladder cancer community with the pharmaceutical companies. Or maybe you'll find your niche maybe in what we're going to be talking about this evening in the grant review process. During our series, we're hoping to answer some of those questions that you may have, and also to inspire some of you to consider joining with us in our research journey.

Now, many experts in the cancer research fields have found, it's very important to hear from actual cancer patients or caregivers like you and I. And it can be very helpful to them in determining areas that needed to be targeted or researched. Now although finding a cure would be our optimal goal, it's certainly not the only measure of progress. For example, the recent use of the new immunology drugs and protocols, have actually changed the face of combating various cancers on many levels. As a result of these new immunology drugs and treatment protocols, some patients have actually won their battles. Thus, applause is warranted for the research it took to bring those options to the table.

Now this evening's speakers are going to attempt to explain why your bladder cancer experience can be so important to come forward and also to give suggestions on how you can get involved in making a difference.