



## **Engaging Patients in Grant Review as a Grant Manager**

### **Bill Russell:**

Our next presenter is going to be, this evening, Donna Kimbark who has her PhD in molecular biology in cancer therapeutics. Now Dr. Kimbark has been the program manager for the Congressionally Directed Department of Defense's Peer Reviewed Cancer Research Program in Washington DC for the last 11 years. That's a mouthful. But being very serious now, that is where millions of dollars come from, in the form of grants to finance much needed research to combat various types of cancers. This year alone, 110 million dollars is available for grant distributions, and bladder cancer will be one of the topic areas for grant consideration. As Ralph mentioned, we both have participated in the Department of Defense grant review program as patient advocate consumer reviewers and found the experience to be extremely interesting and rewarding on many levels. That particular year that I was a reviewer I believe over \$9 million went directly to bladder cancer research. So without any further ado, Dr. Kimbark, I turn it over to you.

### **Dr. Donna Kimbark:**

I'm really excited to be here. I'm dedicated to the bladder cancer community and to the Peer Reviewed Cancer Research Program. We're part of the Department of Defense and being part of the Department of Defense and the Congressionally Directed Medical Research Programs, we do use a two-tiered review process here in programmatic review. Mainly today I'm going to talk about the peer review part of the process.

## Dr. Donna Kimbark:

Consumers, that's what we call patient advocates at the CDMRP, consumers will be the people that will use the products of research. So that's why we use the word consumers. Consumers participate throughout the entire process. Today I'm going to talk to you about peer review, but they are part of programmatic review. And we have a couple of funding opportunities this year that require consumer

advocate participation within the research itself. And I'm not talking about human use as human subjects in clinical trials, I'm talking about being part of the intellectual part of the actual research itself. So we do fund high impact innovative research, as was just mentioned, and we do try to avoid duplication with our other funding agencies such as the NCI. We consider ourselves a complement to the NCI rather than a competitor to the NCI. What we try to do is we find the gaps that the NCI has and we try to fit in those niches and actually try to fill them.

Bladder cancer is a part of the Peer Reviewed Cancer Research Program, as was noted. So how does the evaluation process work? First of all, our peer review process is, we're looking at the technical merit and the impact merit for these award mechanisms. Now, as was mentioned, by Ralph was that a lot of our research applications are basic, but we do have what's called an impact statement, where the PI has to justify why they have this work to do and how it's going to be relevant to patient outcomes in the long term or in the short term. So, there are basic research, there is translational research, there is applied research and clinical research as well. So, this is all a criteria based evaluation of the entire application.

Now how do the consumers participate? You're required to read that lay abstract, we have a lay abstract and a technical abstract. We beg of researchers to actually write in plain language so that you can actually read it on a level that is understandable and free of jargon. I really tell them, "Do not use jargon and acronyms and abbreviations. Don't try to like win the gold medal of abbreviations in one sentence. That's not what we want. And in fact, scientists consider that not very well good grantsmanship that's what we call it, grantsmanship. If you're putting them in abbreviations and it makes you tired to read the sentence. That's not what we want." So we do ask for lay abstracts to be written in plain language, and we ask the consumer to read that lay abstract and that impact statement. But you're welcome to read as many of the components of the application as you want. If you have a science background, go ahead read as much as you want. You're welcome to score as much as you want as well. Whatever you feel comfortable with. That's what we ask.

**DOD PRCRP BACKGROUND**

- Two tiered review process: peer and programmatic review
- Consumers participate throughout the process
- Fund high-impact innovative research
- Avoid duplication with other funding agencies and targets unfunded and unmet gaps
- Bladder cancer included under Peer Reviewed Cancer Research Program (PRCRP)

**PEER REVIEW OF APPLICATIONS**

- **How does the evaluation process work?**
  - Technical merit assessment based on an ideal application
  - Criteria-based evaluation of entire application
- **How do consumers participate?**
  - Required to read the lay abstract and the impact statement; welcome to review all components
  - Clearly review how the research impacts the bladder cancer community – short term or long term
  - Share consumer perspective with leading scientists in field
  - Give strengths and weakness of impact and other components depending on your comfort
  - Score the application
  - An EQUAL voting member

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For more information, see the website: www.prcrp.org  
Bladder Cancer Advocacy Network (BCAN) is a 501(c)(3) non-profit organization. For more information, see the website: www.bcan.org

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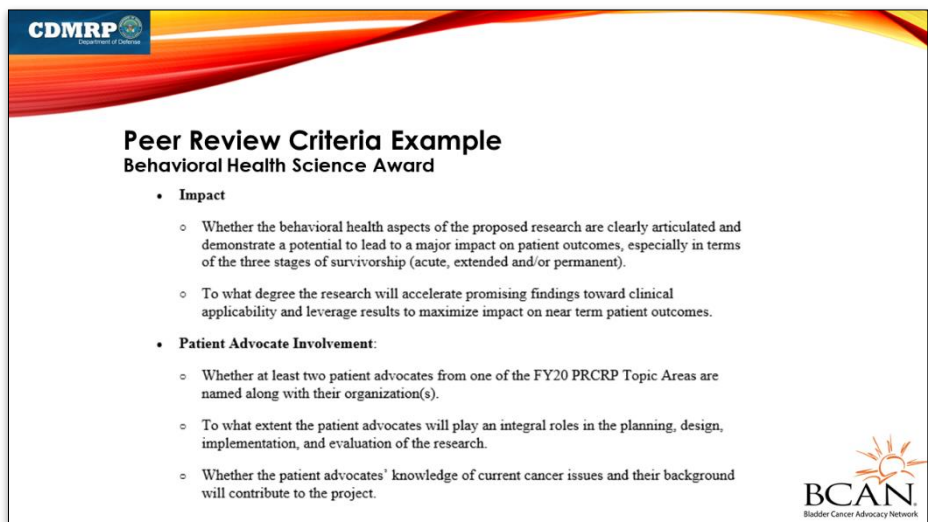
## Dr. Donna Kimbark:

You're going to clearly review the research that impacts the bladder cancer community in short terms and the long term as I said. It's incumbent upon the researcher to justify to you in their impact statement, why this basic research is important to the bladder cancer community. Remember, the foundations of research is basic research, and applied research stands on top of the basic research, translational research then stands on top of the applied research. It's all building up towards those clinical trial and finally towards standard of care and therapeutics. You're going to share your consumer perspective with leading scientists in the field. You'll be sitting on a panel with scientists who want to hear your point of view, and maybe they've never interacted with a patient before. And you're going to open their eyes to this.

Now, because of this very special year that we're in, we're going to hold all of our peer reviews by virtual teleconference this year, just so we can keep our community safe. So we're going to give the strengths and the weaknesses of the impact and whatever other components you're interested in, you'll be listening to the other scientists and possibly the other consumer, give their reflections about the application. And then taking all of that into consideration, you will score the application. You'll score the impact on any other components that you find that you feel comfortable scoring, and you'll also score on the entire application, taking into account everything that you've heard that day about that application from the scientists and possibly the other consumer. You are an equal voting member. So all of your strengths and weaknesses, everything you say are taken into account in their final score.

So a peer review criteria. I just wanted to show you the peer review criteria. Now we have many different types of funding opportunities. I'm only showing one type of application funding opportunity criteria here. Only one type. This is the Behavioral Health Science Award. It's a brand new type of reward mechanism because we have other types of reward mechanisms such as basic type of reward mechanism. The science

with the Petri dishes and all of that, we call that the IDEA award. We also have the Impact Award that has clinical trials included in it. And we have a Career Development Award that includes trying to develop more people and more scientists doing bladder cancer research. But this one is a Behavioral Health Science Award where we are very excited about because it really takes into account the patient's perspective about being a cancer patient, how it affects you in the short term, being an acute survivor, that is someone who has just been diagnosed, or an extended survivor, someone that is going through treatment, or permanent survivor, someone who's 10 years out.



The slide features a header with the CDMRP logo and a decorative red and orange wave. The main title is "Peer Review Criteria Example Behavioral Health Science Award". The content is organized into two main bullet points: "Impact" and "Patient Advocate Involvement". Each main bullet point contains three sub-bullets. The "Impact" sub-bullets discuss articulation of behavioral health aspects, acceleration of findings toward clinical applicability, and leverage of results. The "Patient Advocate Involvement" sub-bullets discuss naming patient advocates, their roles in research, and their knowledge of cancer issues. The BCAN logo is in the bottom right corner.

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### Peer Review Criteria Example

#### Behavioral Health Science Award

- **Impact**
  - Whether the behavioral health aspects of the proposed research are clearly articulated and demonstrate a potential to lead to a major impact on patient outcomes, especially in terms of the three stages of survivorship (acute, extended and/or permanent).
  - To what degree the research will accelerate promising findings toward clinical applicability and leverage results to maximize impact on near term patient outcomes.
- **Patient Advocate Involvement:**
  - Whether at least two patient advocates from one of the FY20 PRCRP Topic Areas are named along with their organization(s).
  - To what extent the patient advocates will play an integral roles in the planning, design, implementation, and evaluation of the research.
  - Whether the patient advocates' knowledge of current cancer issues and their background will contribute to the project.

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## Dr. Donna Kimbark:

So we would like to look at each one of those and we want to know the psychological long term effects. We want to know the long term side effects of having bladder cancer. We know that there's a lot of long term side effects for some people with bladder cancer. And that has to be taken into account and their psychological health as well as their physical health. So that's what the Behavioral Health Science Award is about. So we have a couple of criteria that a consumer reviewer would be taking a look at. Specifically, we'll be looking at the three stages of survivorship; acute, extended and permanent. How this award impacts that. How does it impact an acute survivor, as opposed to an extended survivor? To what degree the research will accelerate promising findings toward clinical applicability and leverage results to maximum impact on near term patient outcomes.

I'm going to go over a little bit more plain language about what this means. Now also, I just mentioned to you that for some of our award mechanisms, we have patient advocate involvement. And what does that mean exactly? Can you go back to the back slide? Go back. Okay. Thank you. So, what does that mean exactly when we have a patient advocate involvement? It means that there's a requirement by the

researcher to bring two patient advocates from the topic area, like bladder cancer, are named after organization. And what extent do those patient advocates play integral roles in the planning, designing, implementation and evaluation of the research?

You're being part of the actual research team itself, not a subject in that clinical trial, but what you're doing is you're actually participating in the designing, and the implementation and evaluation. And then whether the patient advocate's knowledge of current cancer issues in bladder cancer. So this is a great opportunity for you. And their background will contribute to the project. So let's go to the next slide and see what all of this means.

So what all of this means is, okay, reviewing the impact statement, are the goals of the project clear to you? Did you get why that it was going to be an important project? Whether it's basic or not basic, whether it's the Behavioral Health Science Award, or a more basic award mechanism like the IDEA would. Does it show why it would be important to patients? If it's not showing you how it's important to you as a patient, then it's not going to make an impact. It's not going to be relevant. Is there a sense of urgency within the justification in the impact statement itself to the findings being clinical and making a difference in the patient's lives? We want to move forward.

We want patients to understand the science, but we also want the patients to be able to say, "This application is going to make a huge difference in people's lives." Or they're going to say, "This

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**Consumer's Job:**

**Review the Impact Statement:**

- Are the goals of the project clear?
- Does it show why it would be important to patients?
- Is there a sense of urgency to get the findings to the clinical and make a difference in patient lives?

**Review Patient Advocate Involvement Statement:**

- Did the project name 2 advocates?
- Are the advocates more than names? Are they actively involved?
- Will the patients contribute to the project?

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application, I would never participate as someone in this application, in this clinical trial or whatnot." "Why won't you participate?" "Because it's not ethical." Or you're saying something within a basic research. "This basic research, it's not really paying any attention to the long term outcomes."

### Dr. Donna Kimbark:

Now reviewing the patient advocates' involvement. Now, you wouldn't be doing this for all of the different research mechanisms, because of the fact that we're not asking for that. In the Behavioral Health Science Award mechanism, we are asking. So there is criteria based on that. So, did the project name those two patient advocates? Are they in the right topic area for that project? And are the advocates more than just names? Are they fully integrated? We don't want just names. "Oh, I have these people that I know they, they were my patients at one time, so I'm going to put their names on here." No, okay. That's not what we are looking for. We want active involvement. We want to hear the patient's voice throughout that application. Will the patient's contribute to the project itself? How are they contributing to that project as a member of the research team?

So that's just some of the actual types of things that you'll be reviewing. So, how do you get involved? Okay, first of all, the easiest way I can answer that is by going to the bottom of this slide here, and you'll see a link. Okay? And if you don't remember the link, remember the letters, CDMRP and go to your favorite browser and put in CDMRP, and go ahead and click on that link that's going to be consumer involvement.

The slide features a list of ways consumers can participate:

- Consumers participate as
  - Novice (or first time) Reviewers or
  - Mentor (repeat) Reviewers
- Complete Nomination Form
- Personal Statement of Advocacy
- Current Resumé
- Letter of Support from Organization

At the bottom left, a URL is provided: <https://cdmrp.army.mil/cwg>. On the right, a screenshot of the CDMRP website is shown, with the heading 'HOW TO GET INVOLVED' and a 'Consumer Involvement' section. The website screenshot includes a 'Consumer Stories' sidebar, a main text area with a quote, and a navigation menu with icons for 'About Us', 'Frequently Asked Questions', 'Eligibility Requirements', and 'Apply to be a Consumer Reviewer'. The BCAN logo is visible in the bottom right corner of the screenshot.

Consumers participate in two different methods, either as a novice or a mentor. Okay? As a novice, this is the first time you're doing it, and as a mentor, you've done it at least once before. Now, as a novice, you're not going to be thrown to the wolves, okay? You're going to have a mentor who's going to guide you through it. And we have a consumer reviewer administrator, Elena Joos, who is probably one of the most giving and compassionate people that I know.

She will be there to walk you through the process. You'll complete your nomination form. Your nomination form is going to have your basics, your name, your phone number, and all that, your contact information. You're going to have an organization like BCAN be your nominating organization, you're going to put a personal statement of your advocacy. Why do you think this is important to you? Why do you want to be part of the peer review process? Okay, and your current resume and a letter of support from BCAN. So, go right on to that web page and click on it, and start looking around and getting some ideas of patient involvement. Next slide. And that's it from me. Thank you very much.

### Bill Russell:

All right, thank you very much, Dr. Kimbark for your very articulate and interesting presentation. We really appreciate it.