

# Bladder Cancer Summit For Patient and Families

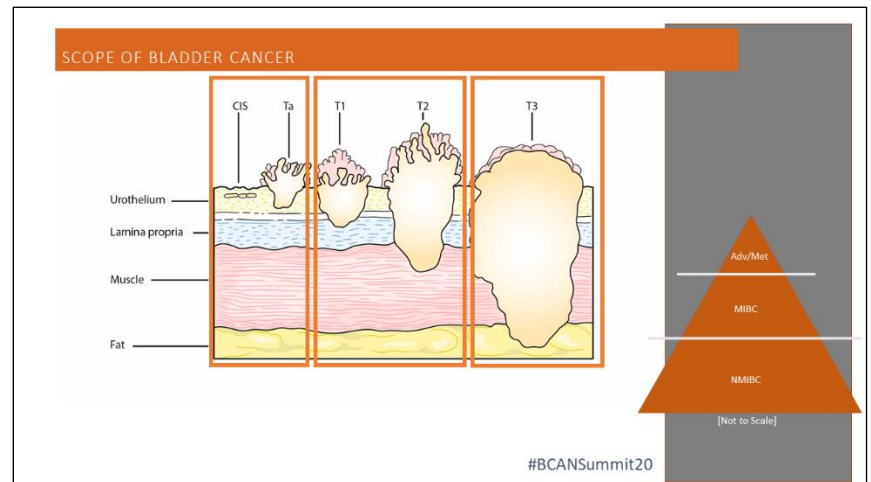
Saturday, October 10, 2020

1:00 – 5:00 PM EDT



## PART 2: BCAN RESOURCES

**Stephanie Chisolm:** Let's take a little bit of a moment to explain the scope of bladder cancer. Bladder cancer is rather unique in that it forms mostly inside the bladder. We have carcinoma in situ here on the very far left, the CIS, followed by a TA tumor. Most bladder cancer tumors are either carcinoma in situ, where they're flat, or they're kind of papillary, finger-like projections. I always think of them as almost like little sea anemones that are waving back and forth inside the bladder. Many people are diagnosed with that.

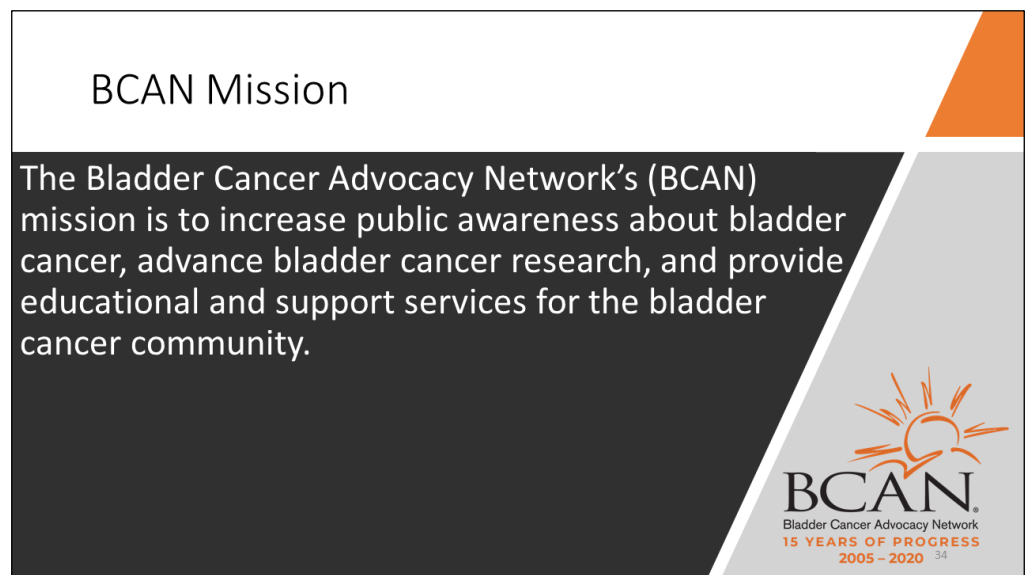


The second largest group that we have are the most invasive. If you could just mute yourself, that would be wonderful. The muscle-invasive group is beginning to invade through the urothelial lining of the bladder into the lamina propria, and sometimes as deep as the muscle itself. When it does get down into the muscle, there's a much greater chance that that cancer will be picked up and spread in other parts of the body.

The third diagnosis for bladder cancer is advanced disease, or metastatic, where it has moved beyond the bladder muscle and into other parts of the body. As you can see on this little pyramid, the bulk of our patients fall within the non-muscle invasive group, but then there's muscle invasive and advanced disease.

Looking at bladder cancer in the United States, we know over 600,000 people that are survivors of bladder cancer today. This year we ranked number seventh as the most common cancer in America. Each year there's roughly 80,000 people who are going to be diagnosed and, this year alone, they estimate about 18,000 people will lose their life as a result of getting their bladder cancer diagnosis. We know that men are four times more likely than women to be diagnosed with bladder cancer and yet, because there's so much confusion and understanding the signs and symptoms, many women receive a much more advanced diagnosis because they don't get in to the urologist, who's generally the doctor that makes that diagnosis for them. That's something that, just to keep in the back of your mind, we know that there are many different people out there that have slightly different information and stories, but that's generally the update on what's going on.

Our mission is, basically, to increase public awareness about bladder cancer, to advance bladder cancer research, as you heard from Diane, and to provide educational and support services for the bladder cancer community. Our mission is played out in so many things that we do that I'm going to highlight for you, but I'd like to ask Andrea to step in and talk a little bit with me about our vision. Our mission is the thing that drives everything we do and our vision is the goal. What would you say is BCAN's vision, Andrea?

A graphic titled "BCAN Mission" with a dark background and white text. The text reads: "The Bladder Cancer Advocacy Network's (BCAN) mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community." In the bottom right corner, there is the BCAN logo, which features a stylized sunburst above the letters "BCAN". Below the logo, it says "Bladder Cancer Advocacy Network", "15 YEARS OF PROGRESS", and "2005 - 2020".

**BCAN Mission**

The Bladder Cancer Advocacy Network's (BCAN) mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

**BCAN**  
Bladder Cancer Advocacy Network  
15 YEARS OF PROGRESS  
2005 - 2020

**Andrea Maddox-Smith:** Thank you, Stephanie. I really appreciate you open it up to me. First, before I get into that, I would also like to thank the sponsors and all the volunteers who helped us make this happen. We paired it this year and this was a big deal to us today and it's going really well. For me to see the few things that are happening here and there, like sharing screens, this is a small organization, but we punch above our weight and I'm very proud of what's happening today with the staff and everything that's going on so I wanted to say that.

But to get into our vision... Simply our vision is a world without bladder cancer. A world where we have treatments that prevent people from dying from this disease. We work very hard on that vision and we try to bring it to life when people engage with us and they feel supported and they have a good experience with BCAN. That's basically our vision.

**Stephanie Chisolm:** Right. Looking at that vision is always the horizon that you might say that there may never be a world without bladder cancer. I think in the meantime, BCAN is really working hard to make sure that everyone is aware, they get in and they get an early diagnosis, and they have, obviously, access to safe and effective treatments, and we're doing an awful lot to ensure the lives of survivors and

the quality of life after their bladder cancer diagnosis. Thanks so much, Andrea, for jumping on. We'll see you a little bit later on when we get into the breakout.

**Andrea Maddox-Smith:** Thanks. Great job, Stephanie.

**Stephanie Chisolm:** Take care. Like any good nonprofit patient advocacy organization, BCAN has three main elements or pillars. We do education and awareness, we support research, and we speak on behalf of the bladder cancer community in the advocacy sense. I'm going to break that down just a little bit and go through these rather quickly. One of the ways that we work to raise awareness is by putting out all kinds of things. We put ads in the AARP magazine and we had all kinds of people contact us when we did that to say, "Wow. I had no idea that you were even there and all of a sudden there you were in my magazine."

Our awareness walks are one of the things that we do. I'm going to talk about that in a second, but in the last couple of years, we have been a founding member of the World Bladder Cancer Patient Coalition and, collectively, we've decided that the hashtag to use for this is to be bladder cancer aware. That's one of the groups that we're very proud to be a member of. Andrea is on the board of directors.

Our virtual walks. These are things that we have been doing, as you saw from Diane, since 2011. This year alone, we were scheduled to have walks in 28 different cities. Of course, the pandemic changed all of that. Walks help raise awareness and they also help to raise funds to support our programs and services that are here to help serve you. We're here to help you and your families to learn about the warning signs, to understand the diagnosis, to figure out what the best treatment options are for you. We help you understand those treatment options. We talk about the quality of life and we address survivorship issues. These are all things that BCAN does. I'd like to say that we're here. Basically you can access us 24/7. We may not always be at work and, obviously, we're not in the office anymore, but we're available online. We keep things up to date so that there are many resources available to you. As Diane mentioned, all of these things are done with the approval and advice and information from over 60 leading physicians around the country to help really review much of our materials.

Let me talk a little bit about some of our free programming that we offer. We have our website. If you haven't visited yet, I'd love for you to go visit [bcan.org](http://bcan.org), and there you'll see some of our webinars where you have a chance to listen in and

actually ask questions of some of the nation's top experts on bladder cancer issues. Obviously we have our summit and we do have print information. I believe most of you who registered early should have received a copy of our tips for caregivers that Diane showed you, along with a copy inside of it of the bladder cancer basics. We will be happy to send it out to anybody else who would like another copy if you haven't already received it. We've done lunch and learn programs to help build communities around the country.



We've been all over the place, and then, of course, COVID hit, where these lunch and learns were to bring experts together and build a community. We switched those over to coffee and conversations. I'll talk about that in just a second. For those who haven't seen it yet, this is our bladder cancer basics. As you saw from the very early edition, this is a little bit more modern looking. It's more updated. It has all of the approved treatments that are here for bladder cancer. It's comprehensive, and yet it's written in plain languages. There's a link inside to all of our website content so that, for people who want to know more, they can go and dig a little bit deeper and have a better understanding. I find very often when many patients are newly diagnosed, they're kind of shell shocked and they just want the very basics and that's really why we keep that name, bladder cancer basics.

It's really meant to give you some good information on which to build your learning. We followed that up this year with help from our care community. We had a number of volunteers who really were very instrumental in developing our tips for caregivers, which is actually a folder that contains bladder cancer basics. You are welcome to ask for some of those as well. They're available, free of charge, on our website and then we're also going to send them out if you would like a copy.

Patient insight webinars. We do more than 10 of them every year. They're great, especially during the pandemic, because you do them from the comfort and safety of your own home. You have live access to the experts and then we archive them. We save those recordings and we break them up into learning chapters so you can go right to the section that's most important to you. We also provide a written transcript so that you can print out a copy, you can highlight things. You can learn what you want when you want because those archive copies are available on our website 24 hours a day, seven days a week.

If you've never joined a webinar, we invite you to do so. You can sign up for any one of the three that we have coming up before the end of 2020.

Those coffee and conversations programs are now really going all over the place and they're being done in conjunction with experts in their communities. They're showcasing what's available in the local hospitals, in their local practices, so that they can help you understand what your resources are. If you're interested in bringing one to your community, I'll give you some information about Morgan's email address later on, but you can send a note to Morgan, or you can fill out the evaluation form and we'll reach out and contact you later about setting one up in your community.

As if we weren't already doing enough, we'd come up with a whole bunch of new things, exciting things, that we'll be offering in 2021. One of the things that's going to be a slight shift on our webinar format are going to be treatment talks. Those will be very specific conversations in the webinar format featuring an expert talking about a particular treatment along with a patient who has experienced that treatment to talk about what their experience was, whether it's BCG or immunotherapy or cystectomy, whatever that treatment happens to be. BCAN is also going to be launching, in the winter time, a health and wellness newsletter to talk about the survivorship and how do you move beyond and how do you live a full and healthy life? We're going to have podcasts that are going to feature experts, not only the medical experts, but sometimes they're going to feature patient experts because you are the experts of living with the disease and you're the ones who know best. These are some things we look forward to in 2021.

As Diane mentioned, BCAN supports research, and I just wanted to highlight some of those aspects of what Diane had talked about a little further. As she said, we did our think tank online this year. We had over 200 participants and they were part of a panel that were discussing BCG unresponsive, non-muscle

invasive bladder cancer, and how we're now looking at having new options for people who don't respond to BCG. That's a pretty significant change because back when BCAN was started, there were no other options.

We do provide research awards. Our top research award is meant to really support the research that is highly innovative. It's what we consider high risk and high reward type of research. This year's award went to Dr. Jeffrey Ravetch. He's a professor at Rockefeller university in New York and his study is intravesical delivery of FC enhanced CD4 against antibody for the treatment of bladder. I'm not a scientist and I look forward to the plain language summary of what he comes up with when he finishes his research in two years. That award is \$300,000 over two years.



We were able to provide three awards to early career investigators like Dr. Yuki Kita. He is looking at defining NRF to induce tumor invasion in bladder cancer.

Dr. Rusty Johnson I know is at Johns Hopkins and he is looking at targeting regulatory B cells to improve anti bladder cancer immunity. Our young investigator award for patient-centered clinical research went to Dr. Matt Mossanen, who you will hear, if you're in one of the non-muscle invasive groups, he is going to be one of our medical moderators. He's really focused on identifying patient and provider factors associated with smoking cessation. He's very much involved in helping us help you to quit smoking when that's an issue because we know that people who are smokers are at greater risk of bladder cancer, and they're also at greater risk, if they continue smoking of having that bladder cancer recur.



Our Bladder Cancer Genomics Consortium is really a research program that consists of a collaboration of eight different leading institutions around the country that is really intended to provide the opportunity for every patient to be an exceptional responder to personalize therapy. I'm really happy to report that we've completed our first trial with over 200 patients. They've had their tumors typed and they know the genomic profile. We've also established a biobank so that research into the genetic changes that lead to changes in bladder cancer can continue because we have these bio specimen.



We know that there are no new treatments without clinical trials. Many of you may or may not have considered a clinical trial. If you're wondering, how do you find a clinical trial? Of course, you can find them on the BCAN website. [Clinicaltrials.bcan.org](http://Clinicaltrials.bcan.org) has a direct feed from the National Institutes of Health and the National Cancer Center and we have all the clinical trials that are just focused on bladder cancer. When you go to [clinicaltrials.gov](http://clinicaltrials.gov), the national website, it can be a little overwhelming to look for

a trial. Ours are only focused on bladder cancer, and there you can search by the type of disease that you have and also you can click many different states. Maybe you live in New York and you winter in Florida. You have a house down there so maybe you could look at something that's going on at the Moffitt Cancer Center in Florida, or at NYU. Maybe your kids live in California, and you could go stay with them for a period of time.

You could look at clinical trials, you could save that trial, you could email that trial to family and your doctor. You can do all kinds of things. If you're interested in clinical trials, and we encourage people to look, just visit our website. Finally, in the research area, one of the things that I think has been very exciting, and many people on this call are part of our Patient Research Advocate Program, where we have worked very closely to help train everybody to really understand the scope of the disease and to be a contributor. Many of our patient research advocates have been on pharmaceutical advisory boards. They've participated in focus groups. We have a really stellar group of people that have gone and been reviewers for some grants through the Congressionally Mandated Department of Defense Research Funds, which is very exciting. They've been advisors on research development teams. If you're interested, send an email to [mstout@bcan.org](mailto:mstout@bcan.org).

Obviously we wouldn't be an organization with advocacy in our name if we weren't speaking up for you on the federal level, and also on the state level and helping to raise awareness. Advocacy really is the process of actively supporting the cause or speaking, or writing in favor of, or defending on behalf of a person or group. That's what we do. We're here for the bladder cancer community. We tend to partner with other like organizations like One Voice Against Cancer or the Rally for Medical Research, but we also go on the Hill. We've done that in the past and it's been a wonderful opportunity when there are issues that are pertinent to the bladder cancer community, we will ask you to help us out. There are a number of things that we have coming up that we're going to be focusing on.

If we have something we want to let legislators know about, we'll send you an email. It'll have instructions. It'll be very easy for you to speak up, as well, on behalf of the bladder cancer community. These are the five issues that we have identified in our Virtual Advocacy Day, which we just held a couple of weeks ago. One is to support occupationally exposed members of our military. We want to make sure that we're protecting Americans with preexisting conditions. Increased funding for bladder cancer research. Make sure that prescription drugs and next generation treatments, like targeted therapies, are covered by insurance. We're advocating on behalf of making sure that BCG shortage is a short shortage. It has gone on for quite some time and we'll be able to address some of that later on.

We have our in-person support groups. We list on our website a number of different support groups around the country by state. If you visit [bcan.org](http://bcan.org), you can find those there. If you know of a support group that should be listed on there, please let us know, send us an email. We know that many of the support groups are not meeting in person anymore. Many of you are members of our inspire community, which is our online chat community, where you can get in there and answer questions and find out from other patients, other caregivers, other survivors, about key issues that are important to you. This is the inspire online community. Morgan is putting a list of resources with hyperlinks into the chat box for you so you can have that whole list and you can get in there and find all of this information.

Even though I'm talking fast because we have a very full program. Our survivor to survivor program is one where many of the people on this call are our volunteers. Perhaps some of you have benefited from having an opportunity to talk with somebody that really understands exactly what you're going through. When you want to know about what's it like to live with the treatment, live through a treatment or any key issues, we can connect you with a patient who has gone through this or a caregiver who's experienced something very similar.



**SURVIVOR TO SURVIVOR —  
TALK TO SOMEONE WHO UNDERSTANDS**

The BCAN Survivor to Survivor program – offers phone support with trained volunteers. They do know what you are going through.

- Call 301-215-9099 or email [MStout@bcan.org](mailto:MStout@bcan.org) to connect

If you are interested in talking to somebody, we match by age and stage and gender so that you get to find somebody out there who really could give you some advice on what they wish they had known. They're not going to give you medical advice, but they do let you know what their questions were because sometimes it's a little overwhelming.

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