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Meet the Expert: Stephanie Chisolm, PhD

Tom Jayram, MD

Advanced Therapeutics Center at Urology Associates, Nashville, Tennessee



Tom Jayram, MD,
moderator



Stephanie Chisolm, PhD

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Meet the Expert

Thank you for joining us today for our final “Meet the Expert” of the year, with our special guest, Stephanie Chisolm, PhD. Dr Chisolm is director of education and advocacy at the Bladder Cancer Advocacy Network, affectionately known to all of us as BCAN (pronounced “Beacon”). I’m your moderator for today, Tom Jayram. I’m a urologic oncologist in Nashville, Tennessee, where I lead a large urologic oncology program at a 30-person private practice group. I am also fortunate to be the editor of the bladder cancer section for *Reviews in Urology*.

The following interview has been edited for clarity and length. The full conversation can be accessed using the QR code provided.

Interview

Stephanie Chisolm, PhD: Hi, Tom. Thank you so much for inviting me to share a little bit about BCAN with you, and I really appreciate the fact that you recognize that we are “Beacon,” like a beacon of hope.

Tom Jayram, MD: Yes. I’ve been very involved in bladder cancer for the majority of my career, and I’m excited to be speaking with you, Stephanie, because BCAN has played a huge role in bladder cancer education and awareness, not just for patients but for health care professionals (HCPs),^a as well.

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Corresponding author: Tom Jayram, MD, Advanced Therapeutics Center at Urology Associates, PC, 2801 Charlotte Ave, Nashville, TN 37209 (gtjayram@ua-pc.com)

Since I was a trainee about 15 years ago, I've been involved with many of BCAN's initiatives. Simply put, they make our lives as HCPs easier and they enrich the lives of patients with bladder cancer. Their resources are terrific, and their communication and messaging are great. BCAN is a one-stop shop for patients in terms of getting more information on their condition, seeing what's new, what's available, and what HCPs are near them who can appropriately address their condition.

So, Stephanie, as a starting point, can you describe BCAN and what the purpose of the organization has been from its conception?

Dr Chisolm: Absolutely. BCAN has been around since 2005. It was literally started at the kitchen table of Diane and John Quale, who were living in the Washington, DC, area. And they were very frustrated. John had been diagnosed in 2000 with bladder cancer, and by 2005, they were appalled at the lack of federal funding for bladder cancer research and the lack of patient information. So they approached John's doctor, Dr Mark Schoenberg, and said they wanted to start an organization.

Dr Schoenberg invited them to go with him to the [American Urological Association] AUA [Annual Meeting] that year, and they met with some of Dr Schoenberg's colleagues on a scientific advisory board. It was evident to them that there wasn't really a career path for scientists or researchers like yourself who wanted to do good for the bladder cancer community. At that time, it was mainly treated surgically. BCG was available, and if chemotherapy didn't work for patients with advanced disease, they were essentially told to "get their affairs in order."

So they decided it was important to start the organization, and BCAN was born.

Our tagline for the first 20 years was "collaborating to advance research." And we do that in so many ways. First, we have plenty of information—I'll talk more in a minute about patient education—but our scientific meeting every summer is the Bladder Cancer Think Tank. For 20 years, it has been the premier science meeting that really focuses on advancing clinical and research components relating to bladder cancer. We now have about 300 people attend who are really

ABBREVIATIONS

ACCC, Association of Community Cancer Centers
ADC, antibody-drug conjugate
AUA, American Urological Association
ASCO, American Society of Clinical Oncology
BCAN, Bladder Cancer Advocacy Network
CME, continuing medical education
GU, genitourinary
HCP, health care professional
NCCN, National Comprehensive Cancer Network
NCI, National Cancer Institute
NIH, National Institutes of Health
VA, US Department of Veterans Affairs

focused on advancing all aspects of research and clinical care.

Our 20th meeting, next year, will be at the end of July. We'll be in Washington, DC, which will hopefully enable many of our friends in the federal community from the [National Institutes of Health] NIH and [National Cancer Institute] NCI to join the conversation to advance research in the bladder cancer space.

We're excited about all the advances that have come about in the last 10 years or so. Now we've got immunotherapies, antibody-drug conjugates [ADCs], precision medicine, biomarkers, and all these other things. So we're shifting our focus a bit to look more at the quality of life for patients, both after bladder cancer and during treatment.

One of the things that Diane and John—who passed away in 2008 or 2009^p—felt was important was showcasing a way that experts like yourself, people who were interested in both research and clinical care, could make a name for themselves as key opinion leaders in the bladder cancer space. So we started giving away young investigator research funds [Young Investigator Awards] back in 2012 or 2013. This year alone, we gave away over a million dollars in research funding, which includes a 2-year [Research] Innovation Award for an experienced investigator doing high-risk, high-reward research. It's a career development award for someone who's trying to get the data they need to go for a large multimillion-dollar grant, say, from the government.

And, then, we still support young investigators. So many of those early-career investigators whom we funded with small grants back in the 2010s and early 2020s are now seen as key opinion leaders in the bladder cancer space. So while there didn't used to be a career path, BCAN helped establish a number of wonderful careers, like yours, in the bladder cancer space, because they got to present their information at our Think Tank and in other areas like AUA and [American Society of Clinical Oncology] ASCO. And we appreciate everything you do on behalf of patients.

Dr Jayram: That's great. One thing you learn as a physician is how much the support of initiatives and advocacy groups really matters. You don't understand that as a trainee, and you don't always understand that when you're seeing patients on a one-on-one level. But when you put a different hat on and you look at the bigger view of what's happening and what you've done every day and what you're trying to accomplish, you realize that you're only as good as the community's level of awareness. Because the information that you provide to people sometimes has flaws, and sometimes it's hard to communicate to certain groups of people. I think BCAN has made great strides in providing a central platform to help HCPs do that.

And the research arm—the funding and the encouragement to young HCPs to embrace bladder cancer treatment—is so important. Bladder cancer is one of the more difficult cancers to treat, so it's not one of those things that everybody who comes out of fellowship runs toward, because the surgeries are hard and the patients are sick. As you know, you can do great work and still have patients do poorly from the disease. It's an uphill battle.

With that in mind, you talked a little bit about immunotherapy and ADCs and all the things we're doing. Because bladder cancer treatment has become such a multidisciplinary disease over the past 15 years, how has BCAN evolved?

Dr Chisolm: In my 10 years with BCAN, I have seen so much growth and change in terms of the types of people whom we deal with.

But first—because you mentioned informational flaws—I'd like to point out that all of BCAN's patient resources are vetted with our Steering Committees and our Scientific Advisory Board. We rely heavily on you all as the key experts in treating and diagnosing and developing a better understanding of risks for bladder cancer. We'd like to think that we have a lot of really good information. “Dr Google” is a scary place, so we hope that patients will quickly find our website, bcan.org.

To get back to your question, I think that we have evolved over time to make sure that we have a multifaceted library of patient resources. And short of doing actual [continuing medical education] CME programs for doctors, we've offered a number of opportunities to enhance science and collaboration to improve patient care. Whether it's our Think Tank or the Specialty Networks meetings we do, we're helping people come together to find better ways to treat this disease that nobody really knew existed. Those are some things that we're very proud of.

Has our population evolved over the years with all of the new treatments? Absolutely. We've been growing our connection to the medical oncology space since before I came, and I really welcome the new tracks in our Think Tank meeting that focus on radiation science and even the role of the pathologist. Especially at the community level, it makes a difference to go to somebody who specializes in [genitourinary] GU pathology, so they can see those nuances that might help you do a better job of treating that individual patient.

Dr Jayram: Stephanie, we talked about research. There are a lot of great things that academic sites are doing with furthering research progress in bladder cancer. But I am a simple community urologist at heart, and what has been really striking to me is the fact that bladder cancer is a complicated clinical disease. The surgeries are complicated, the recoveries are hard, and patients have a lot of comorbidities. So historically, a lot of bladder cancer work was done in academic centers. But I think in the last 10 to 15 years, big organizations like LUGPA and Specialty Networks have helped us organize protocols and expertise, and we've developed a parallel

line of scientific progress at the community level that has been really exciting since the vast majority of early-stage bladder cancer patients are seen in the community. So it's important that community HCPs have access to things like BCAN and the resources that you guys bring. How can community urology better take advantage of what BCAN has to offer?

Dr Chisolm: First of all, everything we do is free. We provide a lot of resources for community-based patients, because we know 60% to 80% of all bladder cancer is treated at that community level. And even if somebody might go to a large academic center to have their surgery, they're going to come back to you for their routine care and maintenance of whatever type of diversion that they have.

We make sure that we have information available in multiple formats, because patients learn differently. We have everything from print materials to our website to short animations that explain complicated procedures. We have a treatment matrix, which helps patients compare different treatment options, and video interviews with patients and doctors about choosing a treatment option. We invite experts like yourself to offer webinars, which stay on our website as long as the content is good. We also have a new app that gives you an opportunity to add your appointments, treatment information, and lab results.

We have a podcast that's led by one of the best patient advocates of all time, Rick Bangs, who has had bladder cancer, has a 2016 model neobladder[®] after his treatment and was very involved as a patient advocate in many research groups. So I invite everybody to listen to "Bladder Cancer Matters," either from your favorite [podcast] app or at bcan.org.

So, there's a whole lot of resources. A lot of it is written on a low health literacy level, because we know that a cancer diagnosis is the first thing that sort of turns off the volume. All patients hear after that is sort of the mumblings of the adults on the Charlie Brown cartoons. People can't focus. And we have information for caregivers, as well. Everything is available at bcan.org.

Dr Jayram: One of the things we had also talked about before, in smaller sessions, is the number of

large community practices that are doing progressive things when it comes to bladder cancer. They run clinical trials, they have novel imaging platforms in their facility, and they have champion doctors who have done a lot of radical cystectomies. They are finding solutions to complex questions in bladder cancer in terms of delivery of care. As you know, there are certain advantages we have in the community in terms of being able to offer newer treatments or research programs that may have lower entry barriers than at other venues.

What are some ways that you think some of these community sites that are doing really good work could partner with BCAN to shine a spotlight on their work and attract a regional base of patients who are looking for a place to go?

Dr Chisolm: We get calls all the time from patients who say things like, "My doctor said they're going to need to take out my bladder, and I don't know where to go to find somebody that knows how to do that." Or, "What am I going to do when I get back? How do I find somebody who knows how to treat me once I have a urinary diversion of some sort?"

Certainly, getting across a state like Texas to one of the academic centers, like MD Anderson or UT Southwestern, might be a challenge. And patients want to be treated in their communities.

So, one of the things that BCAN did, in collaboration with the doctors on ACCC (the Association of Cancer Care Centers), is develop some key elements of excellence in the treatment of bladder cancer. On our website, we have a state map where we list the NCI and [National Comprehensive Cancer Network] NCCN Centers of Excellence, along with [US Department of Veterans Affairs] VA centers. And starting in 2025, we will have a mechanism where practices will be able to add themselves to that list so patients can find local practitioners. So, I encourage HCPs to visit us in January, when that launches.

Dr Jayram: Stephanie, thank you so much for your time. We hope that you continue to be involved, both doing great things with bladder cancer in general but also everything you do out in the community.

Dr Chisolm: Well, I thank you for the opportunity,

and I look forward to seeing many of your listeners at our walks around the country [BCAN Walk to End Bladder Cancer]. So, find us at www.bcan.org.

Dr Jayram: Great. If you'd like to listen to this full interview along with other similar interviews, please visit our website or download the *Reviews in Urology* app, now available in both the Apple App Store and Google Play. And if you'd like to learn more about BCAN and find additional resources, please visit their website at www.bcan.org.

NOTES

- ^a Based on journal style and guidance from the American Medical Association, the term *provider* has been edited throughout this interview to *health care professional (HCP)*.
- ^b John Quale died on June 29, 2008 (<https://bcan.org/story/diane-john-quale>).
- ^c Rick Bangs has a 2006 model neobladder, not a 2016 model (<https://bcan.org/rick-bangs>).

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