OUR MISSION

To increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

1-888-901-BCAN    www.BCAN.org    info@bcan.org
It’s important to know that you are not alone when dealing with a bladder cancer diagnosis. As the Bladder Cancer Advocacy Network (BCAN) remains on the front lines in the fight for its mission to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community, we recognize that we can’t do it alone.

I know that you care about the work we do here at BCAN, so I wanted to let you know how together, we can make an even bigger impact on our future.

Our board, leadership and key volunteers are personally committed to the task of strengthening our legacy to continue this fight against bladder cancer. My hope is that, after you read this issue, you will join us in the fight by considering a planned gift to BCAN.

I would love to have a personal conversation with you and share more information about BCAN’s goals for the future. My hope is that you will take a moment to return the enclosed envelope, and we can schedule a time to talk.

Thank you, as always, for being a part of BCAN. We could not do this work without the support of friends like you.

Sincerely,

Andrea Maddox-Smith
Chief Executive Officer

P.S. I look forward to talking with you and imagining the future together! You can send in the enclosed envelope, or you can just reach out to me directly. My number is (301) 215-9099 and my email is amsmith@bcan.org.
ITEMIZING AND DEDUCTIONS
You can still itemize and deduct charitable gifts. However, the new tax law increases the standard deduction and raises the cash gift deduction ceiling to 60% of your adjusted gross income. If your itemized deductions are nearing the new standard deduction ceiling (for single filers, $12,000; for married couples filing jointly, $24,000), increase or aggregate your charitable gifts over multiple years to make itemizing work for you.

THE BEST GIFTS
Appreciated Securities
The appreciated securities portion of the tax law hasn’t changed. Save capital-gain taxes by donating appreciated securities that you’ve owned for more than a year.

Bequests/Beneficiary Designations
A simple bequest allows BCAN to carry on the work you love and costs nothing during your lifetime. A retirement plan beneficiary designation gift is easy and allows you to leave other assets to your loved ones without the tax implication of leaving your IRA to them. Talk to your advisor to find the best way to meet your objectives.

Tax-Free Rollover from Your IRA
Another portion of the law that hasn’t changed is a rollover from your IRA! If you’re over the age of 70½ and haven’t taken the required distribution from your IRA, ask your IRA administrator to make a direct tax-free transfer to BCAN.
After two TURBT’s for Mike and one for Kristin, this father-daughter team started BCG treatments together. Though they began with the same urologist, Mike’s insurance did not cover his BCG treatments, so he started treatment at the local VA hospital where he received an instillation with mitomycin after his TURBT. Mike is seeing better results now, with no new tumors appearing. While at the VA, Mike also received a pamphlet about BCAN.

We asked Mike and Kristin about what it means to have each other on this journey. “Just having someone else there, who knew exactly what I was going through, and vice versa, helped create more sympathy from others in our household. My mom is all about taking care of us, as much as she can. For her, there was never a doubt,” said Kristin. “But, I think, that for others in our family, it is almost hard to believe, because it’s so unusual for us, as father and daughter, to both have the disease. Others didn’t see the visual effects of losing hair or going through the standard chemo therapy treatments typical cancer patients’ experience. Because they can’t see these common side effects, sometimes people undergoing bladder cancer treatments don’t get that level of sympathy or understanding for the pain they might be going through.”

Mike and Kristin used the same primary care physician. Kristin explains, “She was actually the one who, after my appendicitis, said, ‘I know we sent your dad to the urologist. Because of this shadow on your scan, let’s just be extra safe and have you go see the urologist too.’ If she did not already know what my dad was also going through, I would not have felt that my father’s diagnosis was relevant to tell her about. She may not have thought to send onto the urologist. Using the same urologist who knew that we were both going through this, our entire family was included in the process and that helped us in the long run. We know going to the same family doctor definitely had a lot of benefits in our case.” Mike added, “My son went to see a different doctor in the same urology practice for kidney stones. I think they are doing a better job of checking him, now that we have been diagnosed [with bladder cancer].”

Wife and mother Carol (right) has been there for Kristin and Mike
When asked what message they wish BCAN readers will take away from their story, Mike immediately replied “don’t give up hope. A lot of things start running through your mind when you find out you have cancer. It is a very scary situation. You do not know what the outcome will be, because you can’t get answers right away — that takes time. We just put our trust in the Lord and keep on going with life. We prayed that everything would happen like it’s supposed to. Participating in the BCAN Walk to End Bladder Cancer made me realize, that there are a lot of people out there, and a lot of support. Many people don’t talk about bladder cancer. It threw me for a loop seeing how many people there were at the Walk. Knowing that we’re not alone was important."

Kristin agreed, “The BCAN Walk was definitely comforting. Hearing the doctors speak that day about the advances in treatments, also gives me hope that bladder cancer may not affect my life on the level that I’m worried that it might. It’s easy to panic when you hear the word “cancer.” I was finishing my degree when I was diagnosed, in my last semester of college. I didn’t have room for stress or worry. I just had to say, ‘It is what it is. I’ve just got to trust in the doctors and keep moving forward. The doctors know what they’re doing.’ But do your research and be well-informed yourself, so you know what to expect.”

Read more than 30 stories of patients and caregivers. What is your bladder cancer story?

www.bcan.org/my-bladder-cancer-stories
After 13 years, the BCAN Bladder Cancer Think Tank is still the premier scientific meeting in North America dedicated to bladder cancer. More than 240 attendees met in Denver, the mile-high city, for the 2018 Bladder Cancer Think Tank (TT18).

From its beginning in 2006 as a scientific meeting, the Think Tank was structured as a space to form connections and share ideas, and it has grown both in size and scope. Multiple projects born out of breakout and panel discussions have gained and maintained momentum that extends beyond this three-day meeting. The inclusion of voices from every aspect of the healthcare and research spectrum, in partnership with patients and advocates, creates a unique environment for convergence of perspectives that is conducive to ‘outside the box’ thinking about bladder cancer. The meeting indeed continues to be an opportunity to “Collaborate to Move Research Forward.”

240 attendees came from 32 states and five countries, representing 80 different academic and healthcare institutions.
The first general panel session created a buzz about the Contributions of the Microbiome to Cancer and Bladder Disease. After reminding attendees that “urine is not sterile,” experts provided an overview of the gut and bladder microbiome, its impact on the response to immune checkpoint inhibition, and the potential role the bacterial microbiomes may play in bladder cancer. A panel on Solving the Clinical Trails Conundrum helped to unravel the complexities of the clinical trials process through an interactive discussion among stakeholders including academia, industry, the FDA, and patient advocates. And the final panel addressed Upper Tract Urothelial Carcinoma (UTUC): From Improvisation to Research-driven Care, focusing on the growing understanding of UTUC based on tumor mutational and expression profiling.

BCAN-funded research presentations included The JPB Foundation Bladder Cancer Research Innovation Awardee for 2016, David McConkey, PhD, and BCAN Young Investigator Awardees Rahul Parikh, MD, PhD and Byron Lee, MD, who presented summaries of their research. Our 2018 John Quale Travel Fellowships (JQTF) provided support to enable four talented early career investigators interested in bladder cancer research to come to Denver to present their bladder cancer research interests, and to network with the bladder cancer research community.

Expert lead breakout and working group sessions on Friday and Saturday encouraged in-depth collaborative discussions across a spectrum of issues that are both important and relevant to the bladder cancer community. These discussions focused on topics such as collaborative decision-making, bladder preservation, and survivorship issues. Breakouts also focused on performance measurement and quality improvement initiatives, urinary diversions, strategies and challenges to manage immune-related adverse events in bladder cancer. Additional sessions focused on molecular classification and genomically-targeted therapies or patient-driven endpoints and toxicity thresholds in non-muscle invasive bladder cancer. Palliative care, post-operative intravesical chemotherapy after TURBT, enhanced recovery after cystectomy and identifying immune-oncology combinations to treat bladder cancer, rounded out the discussion groups. BCAN appreciates the efforts of the breakout co-chairs and discussion leaders for sharing their time and talent to make this meeting a fruitful collaboration to advance our understanding of bladder cancer.
DIY Fundraising

Do It Yourself (DIY) Fundraising is an opportunity for people with a deep commitment to the bladder cancer cause to raise awareness and critical funds for the Bladder Cancer Advocacy Network (BCAN) in support of our mission.

This is your activity, which means you get to do it your way, with your ideas and adding your own spin.

Host a fundraising event such as:
• Sporting Tournament
• Gym, CrossFit or Exercise Challenge
• Jeans or Dress-Down Day at Work
• Yoga or Spin Class
• Trivia Night
• Corn Hole Tournament

For more information visit: https://support.bcan.org/diy

Thank you to the TT18 Steering Committee:

Elizabeth Plimack, MD, Chair
Sia Daneshmand, MD, Co-Chair
Matt Nielsen, MD, MS
Piyush Agarwal, MD
David Degraff, PhD
Jason Efstathiou, MD, DPhil
Matt Galsky, MD
Heather Goltz, PhD, LMSW, MEd
Jean Hoffman-Censits, MD
Angela B. Smith, MD
Noah Hahn, MD

Global patient advocate representation at TT18 included the Norwegian Bladder Cancer Society, Bladder Cancer Australia and Bladder Cancer Canada.

“T his climb will be very challenging but the way I see it, that’s no different than what bladder cancer patients go through.”

- Dan Lochner, Patient Advocate
The 2018 BCAN Young Investigator Award will support the research of Philip Abbosh, MD, PhD, Assistant Professor, at Fox Chase Cancer Center, for his work on "Next-generation sequencing to enhance initial staging and dynamically monitor disease response in upper tract urothelial carcinoma (UTUC)." Dr. Abbosh’s research could improve urologists’ abilities to accurately determine the grade and stage of a patient’s disease and allow them to determine if surgery may be avoided and will improve patient outcomes. He notes “This BCAN funding will help determine if urine tests can be used to enhance clinical grading and staging of the disease. If successful, we could potentially use this approach in many other ways down the road too.” Support for this award comes from an anonymous donor.

The Palm Beach New Discoveries Young Investigators Award will further the research of David Oh, MD, PhD, a Post-Doctoral Fellow at the University of California, San Francisco, for his proposal “Modulation of regulatory T cells in the bladder tumor environment by anti-PD-L1 immunotherapy.” We need a better understanding of which patients are likely to respond to immunotherapy. Dr. Oh’s research will improve our understanding of how regulatory T cells can be targeted by immunotherapy to bring benefit to bladder cancer patients. Dr. Oh stated his “research focus is on developing novel immune-based therapies, both in the laboratory and in the clinic where I treat patients with metastatic bladder cancer. We need to improve on the standard of care to benefit more patients. This support will help guide future immunotherapy treatment strategies by focusing on the most critical immune populations, providing broader and longer lasting benefit to metastatic bladder cancer patients.”

Michael M. Shen, PhD of Columbia University Irving Medical Center was selected as the recipient of The JPB Foundation 2018 Bladder Cancer Research Innovation Award. BCAN is pleased to provide this award to Dr. Shen for his work “Modeling bladder cancer metastasis using human patient-derived tumor organoids.” He will examine central questions of bladder cancer biology using a highly innovative approach which may provide the basis for future treatment strategies for bladder cancer. “This award will allow our group to investigate bladder cancer metastasis by building upon our previous work on the establishment of patient-derived bladder tumor organoid lines,” noted Dr. Shen. “We will employ these organoid lines to examine how specific oncogenic drivers may regulate the invasiveness and metastatic ability of muscle-invasive bladder cancer (MIBC), both in cell culture and in mouse models. Our goal is to use these new experimental approaches to provide molecular insights into the lethal properties of human MIBC, which will hopefully lead to improved therapeutic approaches.”

A second Palm Beach New Discoveries Young Investigator Award for Patient-Centered Clinical Research has been granted to Eugene Lee, MD, of the University of Kansas Medical Center for his proposal, “The implementation of nutrition education videos for patients undergoing radical cystectomy.” Removal of the bladder is difficult for patients, especially those with poor nutrition. Dr. Lee will create a video series geared towards helping patients improve nutritional status around the time of treatment. His research will evaluate how well the videos convey the nutrition messages. Dr. Lee shared “As a surgeon and a scientist, I see the potential for improvement in treatment outcomes with improved nutrition education. Our goal is to disseminate our knowledge to a broader audience of patients and caregivers and advance our ability to educate beyond the walls of our clinics.” These awards are made possible by proceeds from the 2017 New Discoveries Research Lecture & Luncheon held in Palm Beach, Florida.
BCAN Congratulates Doctors John Gore & Angie Smith on Receiving a PCORI Award!

Congratulations to Dr. John Gore from the University of Washington and Angie Smith from the University of North Carolina along with a team of researchers who have been awarded funding for a pragmatic (conducted in a real-world setting) clinical study designed to evaluate patient-centered outcomes. Support for this research comes from the Patient-Centered Outcomes Research Institute (PCORI).

Known as CISTO (Comparison of Intravesical Therapy and Surgery as Treatment Options for Bladder Cancer), this study will compare bladder removal with medical therapy. Both patients and their caregivers will share their experiences and outcomes following treatment for up to three years. The goal of this study is to provide information so future patients can choose the treatment that best meets their needs based on the outcomes and preferences of patients like them.

“CISTO is the culmination of a partnership between BCAN, Dr. Angela Smith, and myself, and perfectly illustrates the importance of engaging and involving patients throughout the research process. Through a PCORI Engagement Award, we created the BCAN Patient Survey Network, which allows the patient voice to identify which research questions are most important. A second PCORI Engagement Award supported the PEER program, which helps patients acquire training that emboldens them to participate as research team members. This early work was fed back to PCORI and they made bladder cancer a funding priority. With CISTO, we are taking a research question that patients told us was important, involving patients as research team members who received additional training from BCAN, and answering this research question through a network of BCAN Think Tank attendees.

I am excited about what we will find through CISTO. But more importantly, I am proud of how we got here and thankful to BCAN for the support and partnership.” Dr. John Gore

Partners in this study will incorporate the results in educational materials and practice guidelines to help ensure that providers receive and use the findings from this study when talking with their patients. For more information, visit: www.bcan.org/cisto-bladder-cancer-award/

Bladder Cancer Basics for the Newly Diagnosed

BCAN's handbook is available, free of charge to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. With the help of their medical team, this resource will enable them to make informed choices about their continued medical care.

Available for download or request a free hard copy.

www.bcan.org/handbook
Thank you to everyone who walked, fundraised, volunteered and donated to the 2018 BCAN Walk to End Bladder Cancer events across the country!

Registration begins in October for the 2019 BCAN Walk to End Bladder Cancer. www.bcanwalk.org
BCAN STORE NOW OPEN - SHOP TODAY!

Bladder Cancer Advocacy Network
Leading the way to awareness and a cure

4915 St. Elmo Avenue, Suite 202
Bethesda, MD 20814

Support BCAN.
Get your #BCANOrange gear!

https://stores.inksoft.com/bcan

Support BCAN. Shop today!