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Bladder Cancer Research Saved My Bladder – and My Life

The Journey Begins

Diagnosed with bladder cancer at age 47, Mary Beth Lim recently spoke with BCAN honestly and passionately about the importance of doing one's own research and trusting in the knowledge and expertise of doctors who conduct clinical trials. We also caught up with her doctor, David Y.T. Chen, MD, FACS, professor in the Department of Surgical Oncology at Fox Chase Cancer Center (FCCC) in Philadelphia.

Mary Beth's bladder cancer journey began with her diagnosis in December of 2017. "I was not feeling well. There was blood in my urine. Everything was going wrong," she recalled. "I had a rapid weight gain and my blood pressure was high. I didn't know what it was. I had a multitude of signs."



While attributing the blood in her urine mostly to work stress, she sought medical advice by first going to a clinic, becoming alarmed when the attending physician came back to speak with her. She recalls saying, "If you have tears in your eyes, I hope it's not because of my results?" The doctor replied, "I want you to listen to me very carefully. I need you to take the results of your lab work and go to your regular doctor immediately."

On that recommendation, Mary Beth saw her general practitioner who

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THE BLADDER CANCER ADVOCACY NETWORK MISSION

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

A Note From Andrea...



The theme of this Fall edition of our 2020 newsletter is bladder cancer research, the engine that drives better outcomes for patients and those who love them. One of the reasons that the Bladder Cancer Advocacy Network (BCAN) was founded 15 years ago was to address what was at the time a shocking lack of treatment options or the prospect of new treatments for bladder cancer. Although much progress has been made, there is so much more to do.

Over BCAN's 15 years, we have built a community of dedicated bladder cancer researchers and physicians who work collaboratively to develop new and effective treatments for this terrible disease. Every year, BCAN funds innovative and novel research through our Bladder Cancer Research Innovation Award and the Young Investigator Awards. These awards would not be possible without the generous and ongoing support of donors who enable BCAN to fund nearly half a million dollars each year in bladder cancer research. As of 2020, we have already invested over five million dollars to advance bladder cancer research.

Although it was not possible to hold our annual scientific meeting in person this year, BCAN held a Virtual Bladder Cancer Think Tank that drew over 200 registrants, including patients throughout the country and the world. A host of top bladder cancer doctors and researchers presented their own research into novel ways to address bladder cancer treatments for those non-muscle invasive bladder cancer patients who do not respond to BCG, and I am sure that future collaborations will follow.

While all of our lives have been upended due to the COVID-19 pandemic, BCAN's mission continues unabated to raise awareness of bladder cancer, advance research, and provide education and support services for those who are impacted by what is one of the most common cancers in America. Thank you for supporting our mission by participating in our events, contributing financially or by helping to spread the word about bladder cancer.

A handwritten signature in black ink, appearing to read 'Andrea Maddox-Smith'.

Andrea Maddox-Smith
Chief Executive Officer

P.S. As always, I welcome your thoughts and feedback. Feel free to email me directly at amsmith@bcan.org or send correspondence to the Bladder Cancer Advocacy Network, 4520 East West Highway, Suite 610, Bethesda, MD 20814.

advised her to be seen by her gynecologist. She felt the doctors were overreacting, believing that her symptoms were caused by stress.

The Diagnosis

At the gynecologist's office, Mary Beth learned her test results included what her doctor called "abnormal cells" and "cancer cells." She was told to see a urologist immediately. After driving through a snowstorm to be seen by the urologist, Mary Beth received the terrible news: "The doctor put a cystoscope into my bladder. When he finished, his face said it all. He looked terrible, like somebody died. That's the look I saw on his face. He said, 'I don't know how to tell you this other than you have a very large tumor, larger than a golf ball. It is in your bladder, in the section where your right ureter is.'"

Though shocked and scared, in a strange way the diagnosis made sense to her. "As a kid, I had my ureters reimplanted twice, and I had frequent kidney infections" she said. "The diagnosis just seemed to fit. At the same time, I was shocked, of course. You hear that you have bladder cancer and you think, 'What happened?'"

Her world turned upside down, she drove four-hours to Johns Hopkins Hospital in Baltimore, Maryland for a consultation and potential treatment. There, she was told that she had either Stage III or Stage IV bladder cancer. The treatment option offered to her was a radical cystectomy, having her bladder removed. This seemed like a drastic and terrible option for Mary Beth.



So many things rushed through her mind. Mary Beth spoke to BCAN openly about her concerns which included worries about sexual function after a radical cystectomy: "As crazy as it sounds, I was worried about a sexual relationship with my husband and intimacy. How would that

change for me? It was so important to me that I didn't feel different to him. I worried, of course and my mind went crazy and thinking, oh, my gosh, if I get my bladder taken out, what is that going to do for my quality of life?"

Finding a Clinical Trial

Mary Beth, a self-proclaimed Internet researcher, decided to keep looking. She learned about potential alternative treatment options available in a clinical trial at FCCC in Philadelphia. She told BCAN, "I was 47 at the time. I thought, no way, I can't have my bladder removed. So that was my decision. I told my husband, 'We're going with Fox Chase.' And I did a lot of research on doctors. I knew I wanted to see Dr. David Chen."

He had a really great way about him, very direct and honest and open. That's how I like to hear things. I don't like sugarcoating. He told me everything I needed to know." She also worked with medical oncologist, Dr. Elizabeth Plimack of Fox Chase, who is, in her words, "just awesome." Dr. Plimack also serves on BCAN's Scientific Advisory Board.

Mary Beth was also beginning to learn about the importance of bladder cancer clinical trials, the research studies that attempt to find better ways to prevent, screen for, diagnose, or treat the disease. To be eligible for the trial that Drs. Chen and Plimack were offering, Mary Beth's tumor was tested for the genomic markers that would be a good indication of her likelihood to respond to the proposed treatment.

Dr. Chen said of clinical trials, "To really have the most confidence that what we're doing is right and best for patients, there's nothing more effective in the evidence and the data than a clinical trial." He added, "Mary Beth was very young, and this kind of life-altering event is hard to imagine at such a young age. For some people, the idea of losing their bladder is almost as big a deal as the cancer, and so a clinical trial is a very appealing option."

Dr. Chen recommended a trial for Mary Beth, involving a chemotherapy treatment called "MVAC" - methotrexate plus vinblastine, doxorubicin, and cisplatin. Though Mary

For information about sexuality and intimacy about bladder cancer, visit bcan.org/bladder-cancer-sexuality.

BCAN maintains an up-to-date and comprehensive database of bladder cancer clinical trials. Please visit clinicaltrials.bcan.org to search for a trial near you.

Beth found the process of filling out so much paperwork to participate in the clinical trial “overwhelming,” given her other option, which was having her bladder removed, she opted for the trial.



Mary Beth started her clinical trial with three rounds of the MVAC chemotherapy, which she described as “terrible, just terrible,” and she added, “I think when you get the diagnosis that you have cancer, you’re going to do whatever you can survive. Would I do it again? I think I would.”

Thankfully for Mary Beth, her tumor responded to the MVAC and shrunk dramatically. She has had one recurrence of bladder cancer which was caught early and treated with BCG. Now, two years later, Mary Beth remains healthy and active.

Dr. Chen told BCAN that it’s challenging to hear people talk about clinical trials as a last resort. “It’s not necessarily the end stage when a clinical trial is helpful, but it’s a much broader way of thinking about how to do things. A clinical trial can also address questions like ‘How can we do this better, and how can we improve on something that’s already working pretty well?’”

Given that three out of every four bladder cancer patients are male, and the average age of diagnosis is 73, at times, Mary Beth sometimes felt out of place. She told BCAN, “I think I was one of the very few females on the clinical trial, perhaps one of the youngest, too.”

“[Bladder cancer research] saved my anxiety levels. It saved my peace of mind. It saved my life.”

Connecting to BCAN

While looking for information about her options, Mary Beth spoke with her sister-in-law, a former triage nurse, about her diagnosis who told her, “Go to BCAN.” While at FCCC, her doctors also gave her a copy of BCAN’s *Bladder Cancer Basics* handbook, something that Mary Beth described as invaluable. “There was so much great information there. I liked the fact that there were illustrations of tumors as well as how they are graded and classified.” She also frequently visited the BCAN.org web site, adding, “I would constantly go there when I was looking for information about BCG or the long-term effects of chemo. I found a wealth of information on it.” Dr. Chen added “I think there are a lot of women who struggle to connect or get support, and BCAN has been a huge benefit in that way, to connect women who have been on the same journey.”

Mary Beth added that she would also use the information at bcan.org to keep her family informed, too. “I actually showed my kids what the bladder looked like, and how the tumor was growing. Based on that information, I was able to explain everything to my children, and even to my friends. If they asked, I was able to show them pictures so they could understand my diagnosis.”

Mary Beth has participated in the Allentown, PA, Walk to End Bladder Cancer. She said of the Walk, “I really enjoyed being part of the Pennsylvania Walk because you get to meet so many people that either have bladder cancer, are going through it, or have survived it.”

When asked what advice she would give to current and newly diagnosed bladder cancer patients, she said, “Definitely get checked out, get everything checked out. I went to a urologist who did that scope. And in 30 seconds, he found out that I had a tumor.”

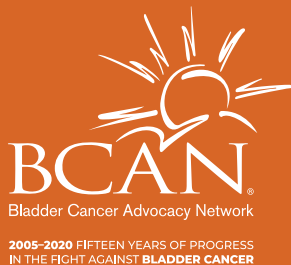
Without a doubt, Mary Beth feels that she owes her life to bladder cancer research, her clinical trial and very good doctors. When asked about the impact of clinical trials and bladder cancer research, Mary Beth said “It saved my anxiety levels. It saved my peace of mind. It saved my life.” 📌



Interested?

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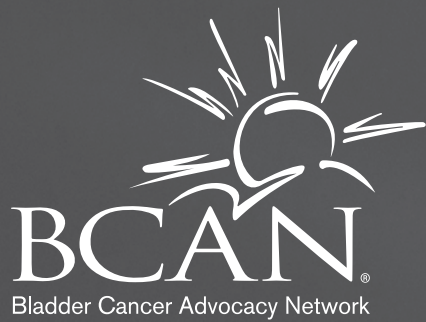
What is a donor-advised fund?

A donor-advised fund (DAF) is a type of giving program that allows you to combine the most favorable tax benefits with the flexibility to easily support your favorite charities.

An increasingly popular charitable vehicle, DAFs are an excellent way to both simplify your charitable giving and facilitate your strategic philanthropic goals.

How does it work?

- Establish your DAF by making an irrevocable, tax-deductible donation to a public charity that sponsors a DAF program
- Advise the investment allocation of the donated assets (any investment growth is tax-free)
- Recommend grants to qualified public charities of your choice



2005-2020 FIFTEEN YEARS OF PROGRESS
IN THE FIGHT AGAINST **BLADDER CANCER**

Your generous donation to the Bladder Cancer Advocacy Network helps us continue our comprehensive approach to fighting bladder cancer while offering hope and support to those who need it most. Contributions help BCAN:

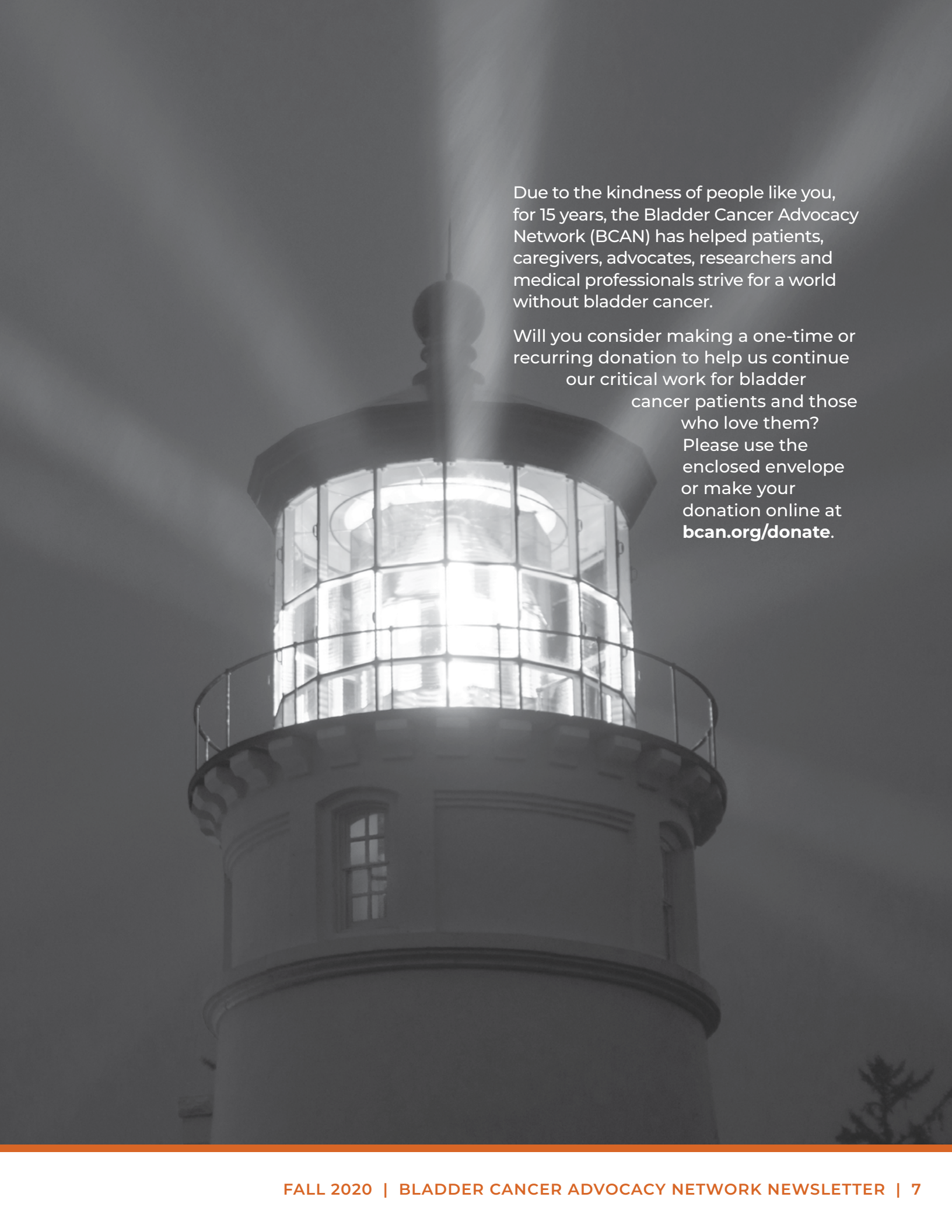
- Fund bladder cancer research, today's engine that drives tomorrow's cure
- Raise awareness of bladder cancer, saving lives
- Provide free education and support services to patients and caregivers



JOIN US OCT 3, 2020
BCAN Fall Virtual Walk to End Bladder Cancer
Visit www.bcanwalk.org

The Fall Virtual Walk is an interactive nationwide event that will involve participants walking from a place of their choosing.





Due to the kindness of people like you, for 15 years, the Bladder Cancer Advocacy Network (BCAN) has helped patients, caregivers, advocates, researchers and medical professionals strive for a world without bladder cancer.

Will you consider making a one-time or recurring donation to help us continue our critical work for bladder cancer patients and those who love them? Please use the enclosed envelope or make your donation online at **bcan.org/donate**.

Bladder Cancer Research: BCAN Research Funding Supports New Awardees, New Approaches

BCAN was founded, in part, because Diane and John Quale were appalled by the lack of research funding to find better ways to treat this disease. Though it was a long time coming, the last few years have brought progress in the diagnosis and treatment of bladder cancer.

Advances in bladder cancer research are the engine that drives innovation and provides better outcomes for patients. From its inception, BCAN has helped improve patient outcomes by advancing the pace and scope of bladder cancer research.

Each year, BCAN awards grants to outstanding researchers and clinicians in the bladder cancer field through its Bladder Cancer Research Innovation Award and its Young Investigator Awards. Since 2009, BCAN has awarded more than \$5 million to promising scientists and research investigators across the country

2020 Bladder Cancer Research Innovation Award

Our Bladder Cancer Research Innovation Award, funded at \$300,000 for two years, supports exceptionally novel and creative projects with tremendous potential to produce breakthroughs in research, treatment and management of bladder cancer. The 2020 awardee is Jeffrey Ravetch, MD, PhD, Professor and Head of the Laboratory of Molecular Genetics and Immunotherapy at Rockefeller University. Dr. Ravetch's project, "Intravesical delivery of FC-enhanced CD40 against antibody for the treatment of bladder cancer," focuses on the mechanisms by which antibodies, the proteins naturally produced in response to infection, function in people. Recombinant antibodies (those made in the lab for treatment purposes) targeting the immune system have significantly improved survival in patients with cancer, including bladder cancer.



Jeffrey Ravetch, MD, PhD of Rockefeller University

Given the success of antibodies generated to block the natural "brakes" that occur within the immune system, Dr. Ravetch's lab has described an alternative strategy to help "step on the gas pedal" of immune cells by targeting a protein called CD40.

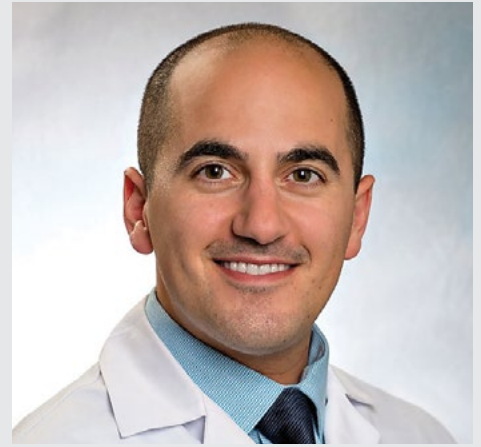
Dr. Ravetch recently told BCAN "Our BCAN funding allows us to initiate the study of a promising immune modulating therapy for NMIBC patients who have not responded to or relapsed on BCG. This academically sponsored program will provide us with much needed insights into the physiology of intravesical therapy and the role of immune responses in the progression of urothelial tumors."



Dr. Yuki Kita



Dr. Burles (Rusty) Johnson



Dr. Matthew Mossanen

2020 Young Investigator Awards

BCAN also supports bladder cancer research via our Young Investigator Awards to support the development of outstanding early career research scientists and clinical cancer research investigators. Our one-year \$50,000 awards fund researchers who are working in a research environment capable of supporting transformational bladder cancer research.

BCAN's 2020 New Discoveries Young Investigator Awards were granted to Yuki Kita, MD, PhD, at the University of North Carolina at Chapel Hill and to Burles (Rusty) Johnson, MD, PhD, a Medical Oncology Fellow at Johns Hopkins University.

Dr. Kita said "This BCAN funding will help us better understand the effects of NRF2 activation in muscle invasive bladder cancer as well as the development of a novel Nrf2 activation mouse model. If successful, we could gain clues for a potential novel therapeutic strategy to suppress invasion and metastasis."

Dr. Johnson told BCAN "My research seeks to identify additional immune suppressive mechanisms that facilitate bladder cancer growth by investigating B cells, which are understudied immune cells in bladder cancer. My goal is to identify B cell specific molecules that can be targeted to improve survival for a broad set of patients with bladder cancer. I am tremendously grateful to BCAN for providing

critical funding which will help me pursue potential bladder cancer focused treatments to transition to clinical studies. "

The New Discoveries Young Investigator Award for Patient Centered Clinical Research was awarded to Matthew Mossanen, MD, MPH. Dr. Mossanen told BCAN: "This grant has been a valuable source of support to help focus on this work. Through interacting with BCAN, we are able to leverage the expertise and opinions of many stakeholders – especially patients – to better grasp this topic and design durable interventions to promote smoking cessation."

Andrea Maddox-Smith, BCAN's CEO, said of the awards, "We are pleased to be able to help our promising, early-career research and established scientists in our collective mission to improve bladder cancer patient outcomes. We are also deeply grateful for the generous contributions of the Palm Beach New Discoveries friends of BCAN who helped make these awards possible." 📌

Think Tank 2020 – Even a COVID-19 Pandemic Can't Stop the Collaboration

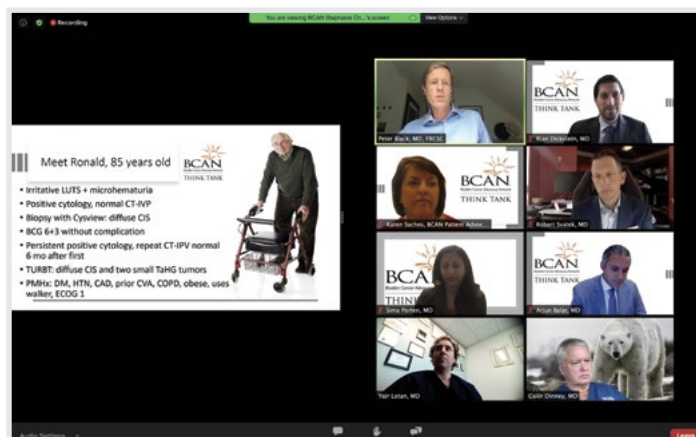
Now in its 15th year, the Bladder Cancer Advocacy Network's (BCAN's) Think Tank continues to be the premier bladder cancer scientific meeting in North America. This gathering of leading clinicians and researchers provides an interdisciplinary and collaborative setting to identify and overcome obstacles while creating solutions in bladder cancer research and treatment.

Like other in-person events planned in 2020, this meeting was transitioned to an interactive virtual meeting conducted online on August 7, 2020. More than 240 clinicians, researchers, and patient advocates from the US and six other countries, viewed presentations from leading bladder cancer experts.

The 2020 Virtual Think Tank discussion on “BCG-Unresponsive Non-Muscle Invasive Bladder Cancer - Time to Recalibrate” was co-chaired by Peter Black, MD, a medical oncologist from Vancouver General Hospital and urologist Colin Dinney, MD of the University of Texas MD Anderson Cancer Center. The meeting was divided into a clinical panel and a translational panel. Both were followed by informative and interactive discussions.

The Clinical Panel included presentations from:

- Peter Black, MD, discussing accurately determining which patients are defined as BCG unresponsive;
- Arjun Balar, MD of New York University Langone Health offering data about the use of pembrolizumab in high-risk BCG unresponsive non-muscle invasive bladder cancer (NMIBC);
- Rian Dickstein, MD of Chesapeake Urology regarding the use of vicineum in BCG unresponsive NMIBC; and
- Colin Dinney, MD, discussing nadofaragene firadenovec, currently a Phase III clinical trial.



Some of the participants of the 2020 Virtual Think Tank discussing BCG unresponsiveness in non-muscle invasive bladder cancer.

Rounding out the presenters was a discussion among the panelists with additional experts Yair Lotan, MD of the University of Texas Southwestern Medical Center, Karen Sachse, a BCAN bladder cancer patient advocate, and Robert Svatek, MD of the University of Texas Health San Antonio.

The Translational Panel included presentations from:

- Max Kates, MD of the Johns Hopkins Greenberg Bladder Cancer Institute detailing information about the PDL-1 checkpoint influencing immune response to BCG;
- Woonyoung Choi, PhD, of the Johns Hopkins Greenberg Bladder Cancer Institute discussing the association of molecular subtypes and BCG responses; and
- Alexander Wyatt, D. Phil, Vancouver Prostate Center and University of British Columbia who offered information about recent study findings exploring links between common genomic driver alternations and BCG unresponsiveness.

After the Translational Panel, the presenters held a roundtable discussion that also included insights from Dr. Dinney, David McConkey, PhD of Johns Hopkins Greenberg Bladder Cancer Institute and Robert Svatek, MD of the University of Texas San Antonio.

We are grateful to both those who participated in the Virtual Think Tank, sharing their valuable insights as well as those who tuned in to the broadcast. BCAN is proud to facilitate discussions that help define priorities for advancing bladder cancer research to improve the diagnosis, treatment and survivorship of bladder cancer.



Alexander Wyatt, D. Phil of the Vancouver Prostate Center who offered information about recent study findings exploring links between common genomic driver alternations and BCG unresponsiveness.

BCAN thanks our 2020 Think Tank sponsors: Astellas-Seattle Genetics, Bristol Myers Squibb, EMD Serono-Pfizer, FerGene, Genentech, Janssen, Merck, Photocure, QED Therapeutics, UroGen Pharma, AstraZeneca Pharmaceuticals and Nektar.

We are all hopeful for a return to the in-person Think Tank meeting in August of 2021 in Denver, Colorado. 📍

Survivor to Survivor

Sometimes, you just need to talk to someone who truly understands.

BCAN's Survivor to Survivor program offers phone support for bladder cancer patients who have questions about their bladder cancer journeys. Many bladder cancer patients want to know more about things like what to expect with a surgery, procedure, or treatment, and how other survivors approach getting back to "normal."

If you are a bladder cancer patient and would like to be matched with a survivor, please call **301-215-9099** and leave a message in **extension 212**. You can also send a confidential email to **mpowell@bcan.org**.

Save time, save paper, get BCAN news faster!

Beginning with the next edition, BCAN will be offering the option of receiving our print newsletter in electronic format only. If you are interested in getting the same great print newsletter content emailed to you as a PDF document, please send an email to **mstory@bcan.org** with:

Your name

Your email address

Your mailing address



The Bladder Cancer Advocacy Network has been recognized as a Top 10 Medical Research Organization by Charity Navigator, the nation's largest independent charity evaluator and leading donor advocate. In addition, BCAN has been ranked as a four-star charity for five consecutive years by Charity Navigator.



Leading the way to awareness and a cure

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Tuning in for these events is easy. Please visit bcan.org for more information.

**Virtual Summit for
Patients and Families**
October 10, 2020
at 1:00 ET

**Fall Virtual Walk to
End Bladder Cancer**
October 3, 2020
at 11:00 am ET

**TALK
WITH US**



**WALK
WITH US**

There are exciting virtual events happening at BCAN in October.
Please **"Walk with us AND Talk with us"** at: