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In Houston, Mike and Kristin share doctors, and a bladder cancer diagnosis

Father and Daughter are Unlikely BCG Buddies

While older men are the most likely to be diagnosed with bladder cancer, imagine our surprise when BCAN met Mike Bartlett and his daughter Kristin Hoisington at the 2018 Houston Walk to End Bladder Cancer. Fifty-seven-year-old Mike was diagnosed with bladder cancer in 2016, after his primary care physician sent him to a urologist to determine the cause of the blood in his urine. Though younger than the average aged patient, Mike attributes his diagnosis to his use of chewing tobacco, a habit he'd had since he was an adolescent. He quit all tobacco products cold turkey with his diagnosis.

The same day Mike was diagnosed, his 31-year-old daughter Kristin had a CT scan because she was ill. She had her appendix removed that night. At first, they thought there was a shadow on the low-quality CT scan. But something on the image was troubling, and her doctor sent Kristin to the same urologist her father had seen. To the family's surprise, Kristin was also diagnosed with non-muscle-invasive bladder cancer just three weeks after her Dad. When they found the tumor, Kristin remembered "the nurse in the room just about lost it, as much as I was losing it. The nurse said 'I have never heard of this. Oh my gosh, your mom is just ... How is your

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OUR 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...



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,

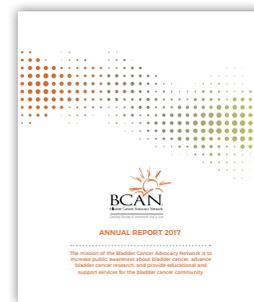
A handwritten signature in black ink, appearing to read 'Andrea Maddox-Smith'.

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.



SAVE THE DATE
11/27/18



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NOW AVAILABLE AT
WWW.BCAN.ORG/REPORTS**



*Making your mark on the future
under the new tax law...*



Donation Strategies that Make the Most of the New Tax Law

CONTACT US:

Anita Parker
Director of Development
301-215-9099 ext. 202
aparker@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.

> Continued from front cover

mom going to handle this?” But Carol Bartlett did handle it. She handled it for her husband, and for her daughter, and even for her son-in-law. “My husband knew, that my mom was going to help take care of me. He could continue working, so we can pay for these treatments,” said Kristin. “Honestly, I did not have any symptoms. If it had not been for having appendicitis, they would have never caught it. It could have been a lot worse than it was. I learned from BCAN.org that women commonly get misdiagnosed over and over. **Even if I had shown symptoms, because of my age, there’s a good chance that the doctors would have still thought it was something besides bladder cancer.**”

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].”



Left to right - Nick Hoisington, Kristin Hoisington, Kyle Bartlett, Carol Bartlett, Mike Bartlett, Lucas Hoisington (front row)

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.”



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.”



The Bartlett-Hoisington Team at BCAN Walk to End Bladder Cancer, Houston, TX, 2018



My Bladder Cancer Story

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

www.bcan.org/my-bladder-cancer-stories



Young Adults



Men



Women



Caregivers

Taking Bladder Cancer Research to New Heights in 2018!

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.



TT18 attendees, Denver, Colorado

Army veterans and patient advocates James Scott and Anne Theriault shared their patient experiences at the Thursday evening Founder's Dinner

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 Trials 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



Army veteran and BCAN Patient Advocate, Jim Scott shares his bladder cancer story



Pro/Am ballroom dancer and Army veteran, Anne Theriault continues to dance through her rare bladder cancer

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.



BCAN Co-Founder Diane Zipursky Quale and the 2018 John Quale Travel Fellows: Nirmish Singla, MD, Arpita Roy, PhD, Panagiotis Vlachostergios, MD, PhD and Shawn Dason, MD.

BCAN would like to thank AstraZeneca, Bristol-Meyers Squibb, Clovis Oncology, Ferring, Genentech, Incyte, Janssen Oncology, Merck, Sensen Bio, Taris, Urogen, EMD Serono/Pfizer, Pacific Edge, Photocure, Seattle Genetics/Astellas, Abbott Molecular and Lilly Oncology for their support of the 2018 Think Tank.

To read more and see photos from the 2018 Think Tank, visit:

www.bcan.org/bladder-cancer-think-tank/



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

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

DIY Fundraising

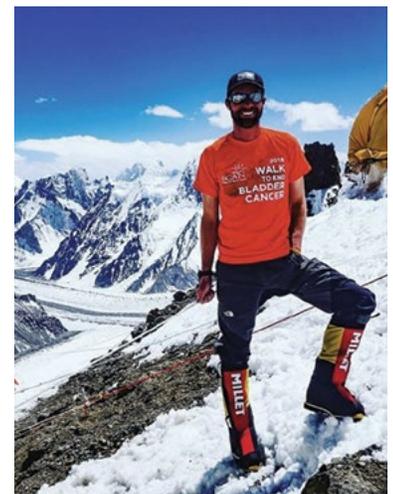
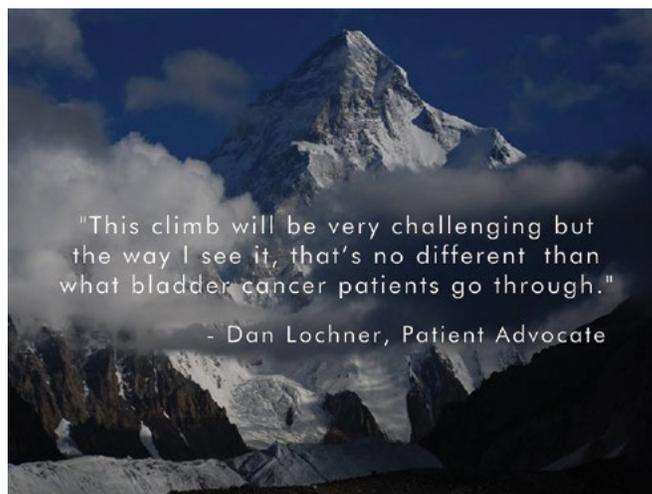
Do It Yourself (DIY) Fundraising is an opportunity for people with a deep commitment to the bladder cancer cause to raise awareness and critical funds for the Bladder Cancer Advocacy Network (BCAN) in support of our mission.

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>



BCAN's Bladder Cancer Research in 2018



Dr. Philip Abbosh



Dr. David Oh



Dr. Eugene Lee



Dr. Michael Shen (on right)

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.**”

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.

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.**”

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



Dr. John Gore



Dr. Angela B. Smith

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





19 STATES
REPRESENTED

27 WALKS

306 TEAMS

OVER 3,000
PARTICIPANTS



**TOP TEAMS
FOR 2018**

Pam's Peeps
(Houston, TX)

Brave for Dave
(NYC)

Team Coffin
(Lehigh Valley, PA)



OVER
\$740,000 IN
FUNDS RAISED
TOWARD
BLADDER CANCER
AWARENESS,
EDUCATION AND
RESEARCH



THANK YOU TO OUR NATIONAL WALK SPONSORS



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



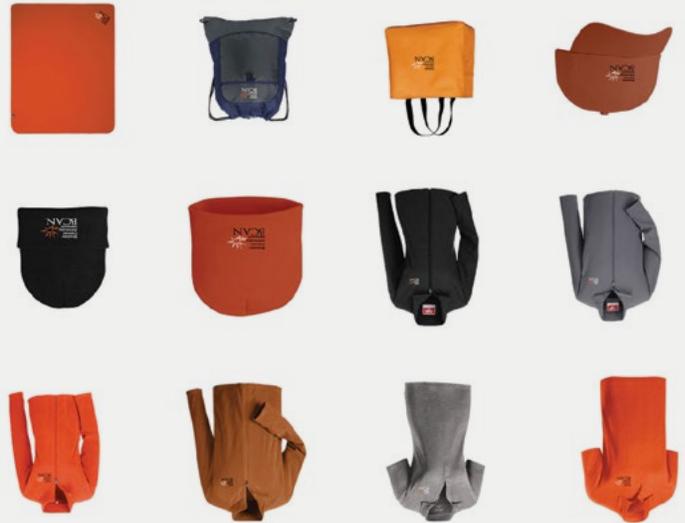
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