

Bladder Cancer Advocacy Network Newsletter

THE BEACON | FALL 2019 | BCAN.ORG



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Dr. Angela Smith is an Associate Professor at the University of North Carolina Department of Urology in Chapel Hill, North Carolina.

For Dr. Angela Smith, Bladder Cancer is About the Patients, Including Her Dad

Dr. Angela Smith, or “Angie,” as her friends call her, is the Director of Urologic Oncology and an Associate Professor at the University of North Carolina Department of Urology. Her career focuses on bladder cancer patients and those who care for them. Her quest is both personal and professional. In addition to being a practicing urologist, Dr. Smith has firsthand experience with bladder cancer. Her father was diagnosed with bladder cancer in 2018 and her grandfather passed away from the disease.

Dr. Smith told BCAN that “It was serendipity that my dad discovered he had bladder cancer. Before an orthopedic procedure, as part of the regular pre op workup, he got a urinalysis to rule out infection. The urinalysis found that there was a microscopic amount of blood in his urine. Her father’s orthopedic doctors sent Angie his medical records for review.

Like most good physician daughters, Dr. Smith reviewed her father’s reports. After his orthopedic procedure was complete and he had recovered, Angie helped him select a local urologist to arrange for a

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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.

1-888-901-BCAN

WWW.BCAN.ORG

INFO@BCAN.ORG

A Note From Andrea...



As we enter the fall of 2019, my thoughts return to our recent, successful Bladder Cancer Think Tank, held in Washington, DC in August. Think Tank remains the premier scientific bladder cancer meeting in North America and provides a collaborative setting to identify and overcome obstacles while creating solutions in bladder cancer research and treatment. Think Tank offers a highly collaborative approach in which researchers and medical professionals share information and resources.

Biomedical research is at its best when the sum of the parts is greater than the whole: collaboration is critical to maintain and increase the pace of bladder cancer scientific discovery. This year, BCAN hosted more than 300 patients, urologists, oncologists, researchers, pathologists, social scientists, caregivers, survivors, patient advocates and industry representatives, all whom are dedicated to improving the diagnosis, treatment and survivorship of bladder cancer.

Think Tank is one of the outcomes of our research program. BCAN also raises funds and awards research grants that help develop lifesaving treatments as well as analyzing other topics that are important to the bladder cancer community, including financial toxicity, caregiving, survivorship and more

Will you consider making a financial gift that will help BCAN's mission of advancing bladder cancer research and supporting those impacted by the disease? You can make a donation by visiting our web site at www.bcan.org/donate or by calling 1-888-901-2226. We exist due to the generosity of others and are deeply grateful.

A handwritten signature in black ink, appearing to read 'A. Maddox-Smith', with a long horizontal flourish extending to the right.

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

BCAN Think Tank Brings Together More Than 300 Doctors, Researchers and Advocates



Some of the 300 Think Tank Attendees in Washington, DC in August 2019.

On August 8-10, 2019, BCAN hosted the premier bladder cancer scientific meeting of the year in North America, the Bladder Cancer Think Tank. More than 300 patients, advocates, doctors, researchers and other medical professionals gathered in Washington, DC to collaborate and advance bladder cancer research and advocacy.

BCAN's Think Tank facilitated crucial discussions that help define some of the priorities for advancing bladder cancer research, including all parts of the patient and caregiver journey, from diagnosis to treatment to survivorship. Meeting attendees included leading urologists, oncologists, researchers, pathologists, social scientists, patient advocates and industry representatives, all of whom are dedicated to improving the diagnosis, treatment and survivorship of bladder cancer.

This year's program included sessions focused on a diverse set of themes, including palliative care, immunotherapy, bladder

preservation, patient-driven endpoints and toxicity thresholds, regulatory science, genomic insights and biomarkers, computational biology and much more.

We are grateful to all of those who attended and we'll see you next year in Denver at our BCAN Think Tank '20.



Matthew Milowsky, MD of the UNC School of Medicine talks about the Bladder Cancer Genomics Consortium while at BCAN's Think Tank in August 2019.



Angela Smith with her dad and daughters.

cystoscopy. “During the procedure, the urologist found a papillary tumor that was resected, and fortunately, it was a low-grade bladder cancer.” Her dad has undergone cystoscopic surveillance since his TURBT. Fortunately, his bladder cancer has not returned.

Like many bladder cancer patients, Angie’s dad shared that he dislikes the pain and discomfort often associated with a cystoscopy. As both a urologist and a researcher, Dr. Smith had been working on this very issue through a grant from the Patient Centered Outcomes Research Institute (PCORI) which focuses on examining methods to reduce the discomfort often experienced with cystoscopies. In late summer of 2019, she submitted a grant application for three million dollars to study interventions that help reduce pain and discomfort related to cystoscopies. Dr. Smith also said that she put together her grant application with the help of BCAN, several urology colleagues, and a number of patient advocates that helped her better understand the problem and how urologists and others can address it.

Both as a practicing urological oncologist and a researcher, Dr. Smith believes not only in delivering care that is focused on patient medical and emotional needs, but also in continuing to do research that is focused on patient outcomes. Dr. Smith recently told BCAN why research that involves patients is so critical to the bladder cancer field. “Research should be done to improve lives of patients. It should be something that changes the patients’ lives for the better. What better way to do patient-focused research than to ask patients directly what would influence and impact them in a positive way?”

Why bladder cancer?

Dr. Smith’s interest in bladder cancer and patient care began at the University of North Carolina Medical School. Being a urologist was “not on her radar screen” when she began medical school. Soon after being assigned a medical school rotation in urology, however, she quickly realized that being a urologist and researcher was what she was looking for in her career. Since urological oncology is one of the few surgical specialties in which doctors can develop a relationship with patients over a long period of time, Dr. Smith jokingly refers to it as the “family medicine of surgery.”

Being a urologist provided more of what Angie was seeking to do as a physician: giving patients personalized attention, building and maintaining relationships, and conducting research in an area that is greatly needed: patient-reported outcomes (PROs). A patient-reported outcome is something that a patient tells either to a health care provider or a researcher about how they’re feeling or functioning. Dr. Smith told BCAN that the critical element of patient-reported outcomes is that they require patient feedback to be successful.

A good example of how patient-reported outcomes help is the critical decision that many bladder cancer patients face: bladder preservation vs. bladder removal. “We’ve been successful in obtaining grant funding to answer this critical research question, which

“What better way to do patient-focused research than to ask patients directly what would influence and impact them in a positive way?”

is comparing the effectiveness of bladder preservation to bladder removal in the case of noninvasive, high risk bladder cancer.” Many patients face this very hard decision. Having information and feedback from other patients about the choices and decision-making processes is crucial.

In addition to patient-reported outcomes, another important role that patients play is helping to develop and expand bladder cancer research. “When we conduct research traditionally, researchers design a study, conduct it and publish results,” Dr. Smith noted. “Wouldn’t it make more sense if a patient also participated in designing and conducting the research since this person is an expert in the experience of having bladder cancer?”

Dr. Smith began collaborating with BCAN in 2013. “My very first interaction with BCAN was through a colleague who recommended me as a panelist to talk about gender issues in bladder cancer. It was a natural fit because some the research I was doing highlighted the issues surrounding women and bladder cancer.” Among other things, she is active in the annual Think Tank patient centered outcomes working group and has helped to design and facilitate several awards to study patient engagement through PCORI. Angie chairs the Scientific Review Group for the BCAN Patient-Centered Clinical Research Young Investigator Awards. After that, Angie was hooked, became actively involved and has never looked back. Before long, Dr. Smith joined BCAN’s patient centered and outcomes policy and working group.



Dr. Smith and a colleague in the operating room.

What advice would Angie give to early-career researchers?

“The most important thing about conducting research is to choose a topic that you are passionate about. You have to choose a topic you believe in. A research career is challenging. It can be difficult to juggle a clinical practice with administrative tasks and research tasks while having personal and family responsibilities. You have to like it so that you have a passion to see it through to completion.” Belief in yourself and your work is key, but it’s also important to have mentors who believe in the work you are doing. “My other piece of advice is to find mentors who believe in you and the research that you believe in. When you have that, it gives you the boost that you sometimes might need in challenging times.”

“The most important thing about conducting research is to choose a topic that you are passionate about. You have to choose an issue you believe in.”

Angie also told BCAN that she was a beneficiary of research grant funding earlier in her own career. “My research got started through two career development awards. These awards provided me an opportunity for protected time to develop my research skills and develop my research topics. Without that protected time as a physician, I would not have had the opportunity to investigate how research fit into my career. Early-career awards are critical to jump start potential researchers before they dive headfirst into clinical practice.”

Angie explains that it is important to maintain perspective. “Have people around you who understand the disease or topic that you are dealing with. For me, that’s my patients. Having them keeps me focused and gives me good ideas. My patient partners are absolutely open to telling me when something needs to be changed or something does not seem right.” She also said “Working so closely with patients makes me a better researcher because I feel confident that what I am doing is going to

improve their lives. We rely on patient input during the entire process.”

Given her years of experience as a practicing urologist, daughter of a bladder cancer patient and a researcher, BCAN asked what Dr. Smith sees on the horizon for bladder cancer patients. She told BCAN “...We have seen tremendous growth in research funding and new drugs because of patient advocacy. The most important thing is to get involved in the bladder cancer space — there are so many ways to do that like working with BCAN. It’s only with patient advocacy that we’ve seen the changes in bladder cancer research and treatment that people have hoped for for decades. Patient advocate involvement can change the face of advancement towards a cure.”



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.

ABOUT ANGELA SMITH, MD, MS

Angela Smith is an Associate Professor at the University of North Carolina Department of Urology in Chapel Hill, North Carolina. She received a BS and BA in biostatistics and music performance as well as an MD and MS in Clinical Research from the University of North Carolina, where she completed her urology residency. She is a urologic oncologist at UNC Lineberger Comprehensive Cancer Center where she treats GU malignancies and serves as Director of Urologic Oncology. She has a background in health services research and biostatistics with particular interests in patient-centered

outcomes research, risk stratification, and quality of care for invasive bladder cancer. She has led three PCORI Awards with the Bladder Cancer Advocacy Network to engage patients in the research process, has been funded by an Agency for Healthcare Research and Quality K08 grant that integrates patient-reported outcomes into post-cystectomy care through mobile health technology, and is currently co-PI of a PCORI large pragmatic trial in bladder cancer. She has previously served on the PCORI Advisory Panel for the Assessment of Prevention, Diagnosis and Treatment Options, representing clinicians.

We're Moving!

BCAN is moving. We will still be in Bethesda, Maryland, convenient to the nation's capital, but as of January 3, 2020 BCAN will be located at:

**4520 East West Highway
Suite 610
Bethesda, MD 20814**

Our phone numbers (1-888-901-2226 and 301-215-9099) will remain the same.

We're always open at www.bcan.org!



My Bladder Cancer Story

Sharing personal stories about bladder cancer journeys helps others. Will you share your story about bladder cancer and BCAN?

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

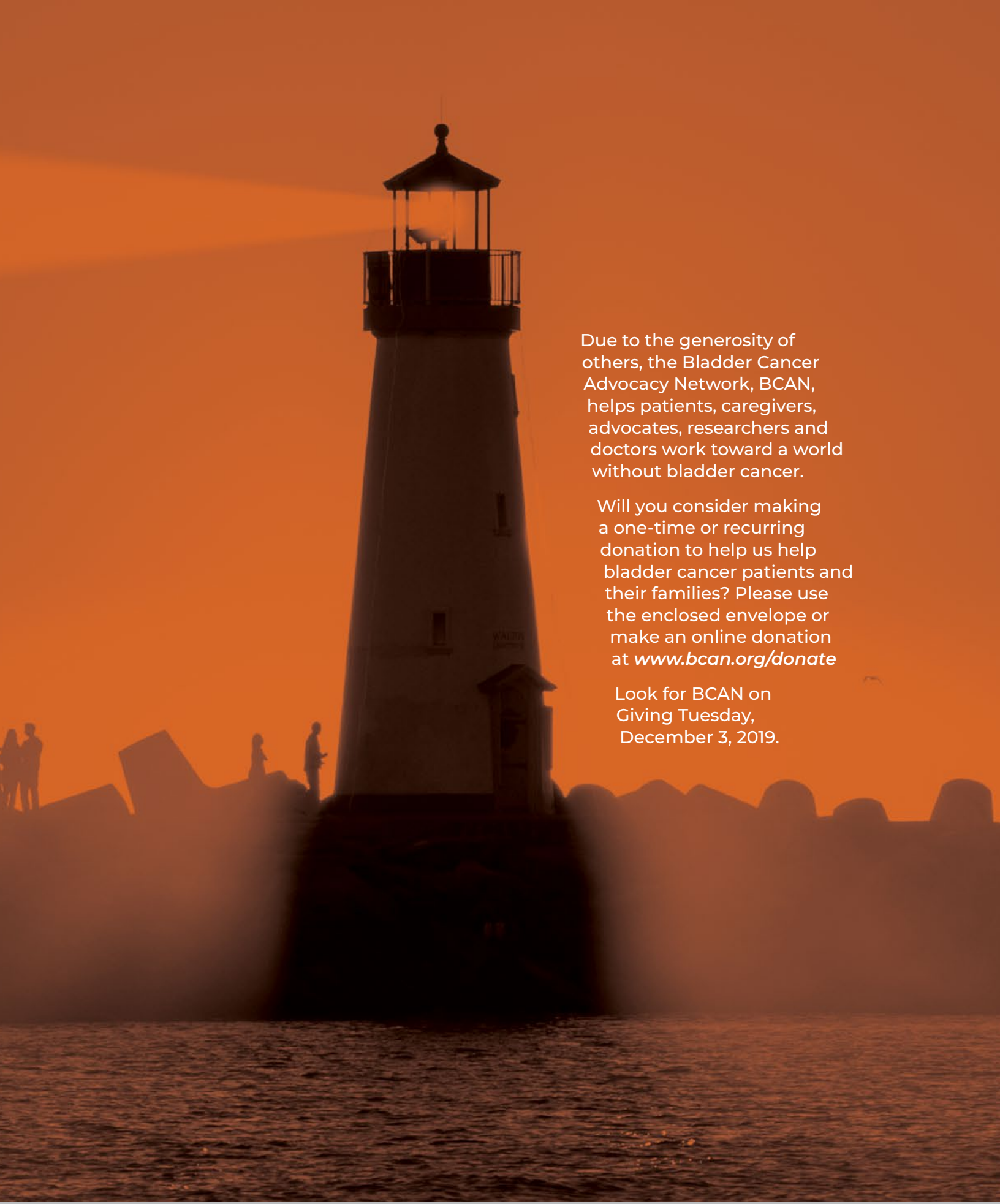




Donations to the Bladder Cancer Advocacy Network support our comprehensive approach to fighting bladder cancer and play a critical role in changing outcomes for this disease. Generous contributions fuel future progress against bladder cancer and:

- Fund research for a brighter future
- Raise awareness that saves lives
- Help BCAN help those who need it most





Due to the generosity of others, the Bladder Cancer Advocacy Network, BCAN, helps patients, caregivers, advocates, researchers and doctors work toward a world without bladder cancer.

Will you consider making a one-time or recurring donation to help us help bladder cancer patients and their families? Please use the enclosed envelope or make an online donation at www.bcan.org/donate

Look for BCAN on Giving Tuesday, December 3, 2019.

BCAN Helps Move Bladder Cancer Research Forward

Bladder cancer is not just one disease; it is a collection of diseases. The more we understand these diseases, the more progress we can make to cure them. Good research is at the heart of current bladder cancer treatments and will continue to be the engine that drives scientific and medical progress against this disease. BCAN is helping to be part of that engine.

From our inception, BCAN has been committed to supporting bladder cancer research that will help improve patient outcomes. Through the generosity of our partners, we help provide critical research funding to continue advancing the pace and scope of bladder cancer research. BCAN has also cultivated strong partnerships with the leading members of the bladder cancer medical community to encourage collaboration among all the parties dedicated to the study of bladder cancer and its prevention, diagnosis and treatment. Among the research grants that BCAN offers are the Bladder Cancer Research Innovation Award and the Young Investigator Award.

“Based on our studies of the biology of bladder cancer, this funding will support our efforts to develop novel diagnostic and treatment approaches for this condition.” — Philip Beachy, PhD

BCAN's Bladder Cancer Research Innovation Award, funded at \$300,000 for two years, supports exceptionally novel and creative projects with great potential to produce breakthroughs in research, treatment and management of bladder cancer. The 2019 awardee is Philip Beachy, Ph.D., Professor of Urology and Developmental Biology at the Stanford University School of Medicine. His



Philip Beachy, PhD, Stanford University

research project addresses the need for better treatments for recurrent bladder cancer CIS (carcinoma in-situ) and intermediate and high-risk non-muscle invasive bladder cancer (NMIBC).

Dr. Beachy's project "Transdifferentiation of fibroblasts to urothelial progenitors for definitive urothelial replacement therapy in non-muscle invasive bladder cancer," also involves replacing the diseased urothelium with healthy bladder urothelial progenitor cells.

Dr. Beachy told BCAN, "I'd like to thank the Bladder Cancer Advocacy Network for their funding. Based on our studies of the biology of bladder cancer, this funding will support our efforts to develop novel diagnostic and treatment approaches for this condition."

"The Bladder Cancer Research Innovation Award supports research that is high-risk and has the potential for high-reward in new discoveries," said Andrea Maddox Smith, CEO



Dr. Sumeet Bhanvadia of the University of Southern California; Dr. Neelam Mukherjee from the University of Texas, San Antonio; and Dr. Sarah Psutka from the University of Washington

of the Bladder Cancer Advocacy Network. "These critical projects are not likely to be funded elsewhere. We are proud to continue to encourage innovation in the bladder cancer research community."

BCAN also helps support cancer research via our Young Investigator Awards. These awards support the development of outstanding early career research scientists and clinical cancer research investigators. Young Investigator Award recipients have demonstrated a commitment to improving the understanding and treatment of bladder cancer.

These one year, \$50,000 awards fund researchers who may be working in basic, translational, clinical, epidemiologic, bioengineering or any other scientific or research field, but are also working in a research environment capable of supporting transformational bladder cancer research.

This summer, BCAN was proud to select three recipients of its New Discoveries Research Young Investigator Awards. This year's awardees are Dr. Sumeet Bhanvadia from the University of Southern California, Dr. Sarah Psutka from the University of Washington and Dr. Neelam Mukherjee from the University of Texas Health Science Center, San Antonio.

Dr. Bhanvadia's research proposal is "Understanding the Burden and Impact

of Financial Toxicity in Bladder Cancer—A Mixed Methods Study of Two Diverse Patient Populations." Dr. Bhanvadia is Assistant Professor of Urology at the University of Southern California and her study is focused on assessing the extent of financial toxicity experienced by bladder cancer patients across a broad range of race, ethnicity, insurance types and socioeconomic status.

Dr. Mukherjee's research proposal was "Recombinant CCL2 as a Novel Treatment Strategy for Bladder Cancer" Dr. Mukherjee, a BCAN John Quale Travel Fellow in 2017, is a post-doctoral fellow at University of Texas Health Science Center in San Antonio and her research is focused on studying how immune cells are recruited into the body environment.

A New Discoveries Research Young Investigator Award was also presented to Dr. Sarah Psutka for her research proposal, "Quantifying Risk and Resilience Among Patients with Bladder Cancer: A Novel Personalized, Comprehensive Risk Stratification Program." Dr. Psutka is an Assistant Professor at the University of Washington and her research proposal addresses the need to identify a more objective way for physicians to assess a patient's ability to tolerate surgery. Dr. Psutka expressed appreciation, saying "I feel incredibly grateful to BCAN for supporting my research into personalizing the risk stratification of bladder cancer patients."

That's a Wrap! BCAN's 2019 Walk to End Bladder Cancer

The Walks to End Bladder Cancer are BCAN's signature awareness events and take place in numerous cities in the United States, principally in May, which is Bladder Cancer Awareness Month. This year, BCAN organized Walks to End Bladder Cancer in 25 cities in the United States, involving more than 3,500 enthusiastic participants and volunteers and raising more than \$650,000.

Walks are a good way to get some spring sunshine and exercise while supporting friends and family, celebrating survivors, or honoring the memories of those who have succumbed to bladder cancer.

The Walks to End Bladder Cancer raise awareness, raise spirits and raise funds. BCAN's walks generate critical funds that enable BCAN us to offer educational resources and support programs free of charge, advance research, serve more patients and families, and continue as the leading provider of bladder cancer



services and information in the United States.

Dave Dimick, a bladder cancer survivor and Walk participant, told us "...This was my third year as team captain of Brave for Dave. It never ceases to amaze me how generous and supportive my family, friends and acquaintances are. It is very gratifying to raise money and be part of the BCAN team and to help others who are fighting this disease."



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— DAVE DIMICK, BLADDER CANCER SURVIVOR

WWW.BCANWALK.ORG



Becoming a BCAN team captain has helped my family and I keep my dad's memory alive through the annual Walk to End Bladder Cancer. This walk has afforded us the opportunity to not only raise awareness about this illness, but to also have an annual day to honor my dad, while celebrating survivors, new research, and the overall progress made in the fight against bladder cancer!

— JAMIE REYNOLDS

WWW.BCANWALK.ORG

Jamie Reynolds said that becoming a BCAN team captain helped her family and her to keep her dad's memory alive. She said, "This walk has afforded us the opportunity to not only raise awareness about this illness, but to also have an annual day to honor my dad, while celebrating survivors, new research, and the overall progress made in the fight against bladder cancer."

BCAN staff are planning even more Walks to End Bladder Cancer in 2020, from California to Florida, and from Denver to Detroit. If you would like to participate in a Walk in one of the cities listed, please contact our Walk team at walk@bcan.org or by phone at 301-215-9099. Online registration for the Walks will open October 1.



WALK WITH US

Register today to participate in a 2020 Walk to End Bladder. Find a location near you and register today at bcan.org/walk.

2020 WALK TO END BLADDER CANCER LOCATIONS

Albany, NY
Baltimore, MD
Boston, MA
Central Ohio
Chapel Hill, NC
Chicago, IL
Cleveland, OH*

Detroit, MI
Houston, TX
Jersey Shore, NJ
Kansas City, MO
Lehigh Valley, PA
Long Island, NY
Northeast TX*

Nashville, TN
New York, NY
Pennsauken, NJ
Philadelphia, PA
Pittsburgh, PA
Denver, CO*
Miami, FL *

Richmond, VA
San Diego, CA
San Francisco, CA
Seattle, WA
Washington, DC

**Indicates a tentative walk city*

Nutrition and Bladder Cancer

Good nutrition is important for everyone, but balanced, healthy diets are strongly recommended for those undergoing bladder cancer treatments. Everyone can benefit from knowing more about how good nutrition impacts cancer prevention, treatment and survivorship. At the Bladder Cancer Advocacy Network (BCAN), we have produced a series of videos that provide important information about nutrition tips, how to prepare tasty, healthy recipes, and how to incorporate a healthy diet into your lifestyle.

Using the search feature on BCAN.org, you can find “Conversations: Let’s Talk About Bladder Cancer” videos that feature BCAN Co-Founder Diane Zipursky Quale, Dr. Jill Hamilton-Reeves from the University of Kansas Medical Center, and Laura Pole, an oncology clinical nurse specialist at the Smith Center for Healing and the Arts in Washington, D.C. These videos offer expert advice about healthy eating with and after bladder cancer, as well as address important issues like changes in taste while undergoing chemotherapy and other changes to patients’ digestive systems during and after treatment.

BCAN works to ensure that our video content is most helpful to those we serve. Using our Patient Survey Network, we conduct periodic surveys to help ensure that our content reflects the wants and needs of bladder cancer patients and those who care for them.

At the same time, BCAN awards research grants that help address some of the critical issues that arise in our patient research, including nutrition. For the first time, in 2018, BCAN awarded a research grant specifically for patient-centered clinical research. The first awardee of the Palm Beach New Discoveries Young Investigator



Award for Patient-Centered Clinical Research was Eugene Lee, MD, whose proposal studied nutrition education videos for bladder cancer patients who were going to undergo a radical cystectomy. A radical cystectomy is major surgery where the bladder and potentially other organs are completely removed. Having your body in optimal condition for the surgery is important and you can help do that by having good nutrition.

Dr. Lee’s research project resulted in a series of videos in which he notes that removal of the bladder is extremely difficult for patients, but especially in patients who have poor nutrition, and the videos are geared towards helping improve their nutrition and making their bodies stronger as they prepare for surgery and treatment.

Dr. Lee’s videos are not technical, are easy to follow and offer tasty and healthy recipes. On BCAN.org, we also have many other videos with important information about diet and nutrition, including the “Conversations: Let’s Talk About Bladder Cancer” video series.

We invite you to peruse our videos on bcan.org and enjoy tasty and healthy living.

Bon Appetit.



SOUTH FLORIDA WALK TO END BLADDER CANCER

Join the Bladder Cancer Advocacy Network and
The Philippine Nurses Association of South Florida

LOCATION: Coral Reef Park, 7895 SW 152nd Street, Palmetto Bay, FL 33157

Check-in: 8:00 am
Walk Program: 9:00 am

REGISTER NOW
support.bcan.org/miami2019

We have one final walk in 2019! Please join us at our South Florida Walk to End Bladder Cancer on Saturday, November 16, 2019. For more information or to register, please visit <http://support.bcan.org/Miami2019>.

A gift anyone
can make?
What's not
to like?



It's true.

By making us the beneficiary of your will or revocable trust, you'll help guarantee our financial strength tomorrow, without affecting your cash flow or your family's financial stability today.

It's an easy gift to help those affected by bladder cancer for generations to come.

Interested?

For more information about this and other planned giving opportunities, visit:
bcan.plannedgiving.org

Or contact:

Anita Parker
aparker@bcan.org

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Leading the way to awareness and a cure

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BCAN'S ANNUAL WALK TO END BLADDER CANCER WILL TAKE PLACE IN 25+ CITIES IN THE US IN 2020.

The Walk to End
Bladder Cancer is
a great way to get
some exercise and
help those most
impacted in the
bladder cancer
community.



TO FIND A WALK NEAR YOU, PLEASE VISIT BCAN.ORG/WALK OR CALL 1-888-901-2226.