

Bladder Cancer Advocacy Network Newsletter

THE BEACON | WINTER 2021 | BCAN.ORG



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Dr. Kent Mouw of the Dana Farber Cancer Institute and Dr. Sarah Psutka of the University of Washington, bladder cancer experts who will be fielding questions at the 2021 Ask the Experts event.

Got Questions? Ask the Bladder Cancer Experts on May 26, 2021

For nearly a year, the global COVID-19 pandemic has woven the fabric of our lives. These unusual pandemic circumstances have, however, created an opportunity for BCAN to reach a broader audience with our quality programming using online tools like Zoom and social media.

In 2021 and as part of Bladder Cancer Awareness Month, we are pleased to be hosting our first-ever *virtual* Ask the Experts (ATE) event on May 26, 2021. Past ATE programs have taken place in Palm Beach, Florida and proceeds from generous donors have funded BCAN's Young Investigator Awards.

This year, attending ATE is free – all you need is a computer, tablet or smartphone. Ask the Experts 2021 will be an interactive program providing an excellent opportunity for bladder cancer patients to interact with two leading doctors

To register to be part of this year's free "Ask the Experts" event on May 26, please visit bcan.org/ask.

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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

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A Note From Andrea...



For many of us, 2020 was one of the most trying years of our lives. The global pandemic and resulting economic situation strained many of us both emotionally and financially. While medical distancing changed the way that we interact with our doctors, telemedicine and some of the associated technologies have helped us stay connected. We have missed seeing our friends in person, but Zoom, web sites and social media have been a blessing that have helped us remain united as a community and stay supportive of each other.

BCAN has adapted to our realities as well; if you would like to learn more about the free online and print resources we provide, please visit us at [BCAN.org](https://bcan.org).

In addition to looking back at the past year, I also look forward to the positive things that will happen in 2021. For example, May is Bladder Cancer Awareness Month and we have a host of activities planned. These include our Virtual Walk to End Bladder Cancer, an Ask the Experts live video event as well as daily activities that will bring attention to and raise awareness of this terrible disease.

We kick off May with our Virtual Walk to End Bladder Cancer on Saturday, May 1, 2021. As with our two Virtual Walks last year, during our live broadcast on BCAN social media channels, we will feature members of the bladder cancer community, including patients, caregivers, advocates, sponsors, volunteers, researchers, and medical professionals. I encourage you to not only register for the Walk on May 1, but also to create a fundraising page and help us work towards our goal of a world without bladder cancer. You can register for free at bcanwalk.org or through the Walk with BCAN App.

As you will read in the pages that follow, on May 26, 2021, BCAN will be hosting a free “Ask the Experts” online event that will connect patients and caregivers with two leading bladder cancer experts, Dr. Sarah Psutka of the University of Washington, and Dr. Kent Mouw from the Dana Farber Cancer Institute in Boston. Both doctors will take questions from our viewing audience and address topics of concern to the bladder cancer community. Registration is free at bcan.org/ask.

Finally, BCAN is offering a host of new and informative programming in the coming months including our popular Patient Insight Webinars, our virtual Patient Summit and new offerings like our Treatment Talks and “Bladder Cancer Matters” podcast.

I can't wait to “see” many of you at these exciting activities.

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

Andrea Maddox-Smith
Chief Executive Officer

P.S. As always, I welcome your input and feedback. Please feel free to reach out to me via email at amsmith@bcan.org.

in the field. This year's ATE bladder cancer experts are Sarah Psutka, MD, MSc. of the University of Washington Medicine and Kent Mouw, MD, PhD of Dana Farber Cancer Institute.

Dr. Psutka is a urologic oncologist specializing in bladder, renal, testicular and prostate cancer. She is also an assistant professor in the Department of Urology at the University of Washington School of Medicine. Dr. Mouw is a radiation oncologist and is the Co-Director of the Dana Farber Cancer Institute Bladder Cancer Center and he also serves as an Assistant Professor of Radiation Oncology at Harvard Medical School.

Ask the Experts Proceeds Fund Bladder Cancer Research Awards

In addition to being leading physicians in their fields, Drs. Mouw and Psutka have an additional connection to BCAN. They were both recipients of BCAN's Young Investigator Award (YIA) that supports the development of outstanding early career research scientists and clinical cancer research investigators who are committed to improving the understanding and treatment of bladder cancer. Dr. Psutka received her award in 2019 and Dr. Mouw in 2016.

BCAN launched the Young Investigator Awards in 2013 to help early career investigators contribute to the understanding of bladder cancer while establishing their own careers. Since that time, BCAN has made 21 Young Investigator Awards grants that have funded research to help better understand the disease and improve patient outcomes. Research funded by the generosity of BCAN donors includes projects about immunotherapies, tumorigenesis, risk stratification, patient education, financial toxicity, and many other topics.

BCAN recently caught up with Dr. Kent Mouw and he described how research support from BCAN has furthered his career: "My Young Investigator Award (YIA) has really been a springboard for me. When my YIA was awarded, I was at the end of my training period and was launching my career in bladder cancer

research. The YIA helped lay the groundwork for much of the work that I have continued as an independent investigator. I run my own research lab now, and many of the bladder cancer questions that I examined as part of the award funded by BCAN helped crystallize much of the research that I am doing today."

Diane Zipursky Quale, BCAN's co-founder, said "The YIA program was started because BCAN recognized the critical need for more funding for bladder cancer research. Most often, securing that first grant is the most difficult step in becoming an independent researcher. By supporting early career investigators who had demonstrated an interest in pursuing bladder cancer research, we felt we would have the greatest impact on ensuring that the 'best and the brightest' were given both the financial support and the encouragement to continue to devote their expertise to finding better treatments for the disease and improving patient outcomes."

"One of the real pleasures I have is interacting with patients, patient advocates and patient families. For me, that's a real joy and a motivating factor."

— Dr. Kent Mouw

Interacting with Bladder Cancer Patients at "Ask the Experts"

As for the opportunity to interact with a live audience at the Ask the Experts event, Dr. Mouw added "One of the real pleasures I have is interacting with patients, patient advocates and patient families. For me, that's a real joy and a motivating factor. It's so important to meet more patients who are suffering from these diseases and whose lives we are trying to improve."


Dr. Mouw also said "It is great to be able to take

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a step back and to talk to patients and families directly to learn what is impacting them. I think that helps recalibrate and understand or really emphasize the things that are important.”

Having the ability to fund up-and-coming early career bladder cancer researchers and doctors is made possible by the generosity of BCAN donors. Even in these trying pandemic times, the members of the bladder cancer community have provided phenomenal support that enables BCAN to continue to provide free educational and support services as well as fund critical bladder cancer research.

In 2021, BCAN will fund four Young Investigator Awards. Your support will help BCAN continue our investment in young, bright doctors and researchers who are working to find tomorrow’s cure.

Ask the Experts registration is free but required. Learn more and sign up at bcan.org/ask. 



Drs. Trinity Bivalacqua and Elizabeth Plimack along with BCAN co-founder Diane Zipursky Quale at Ask the Experts in March 2020.

New in 2021: BCAN Podcast About Bladder Cancer

BLADDER CANCER MATTERS PODCAST

PRESENTED BY BCAN
BLADDER CANCER ADVOCACY NETWORK


BCAN has launched an exciting podcast series by, for and about the bladder cancer community, “Bladder Cancer Matters.” In each podcast episode, host Rick Bangs interviews bladder cancer doctors,

patients, social workers and more to get you the information you need.

Tune in now and listen to some of the best bladder cancer content available. Current episodes include “What’s Up with Bladder Cancer and BCG” with Dr. Ashish Kamat, a two-part episode about when and how to engage with an oncology social worker with Dr. Heather Goltz. Another popular episode is about COVID-19 vaccines for bladder cancer patients

with urologist Dr. Seth Lerner and immunologist Dr. Laila Woc-Colburn.

Getting this great content is free and easy. To listen and subscribe to the podcasts so you won’t miss an episode, simply visit Apple Podcasts, Google Podcasts, Spotify or your favorite podcast site and search for “Bladder Cancer Matters.” If you would like to listen to the podcast episodes on the BCAN web site, please visit bcan.org/podcasts.

Sponsorships are available. If you are interested in sponsoring, please contact Anita Parker at aparker@bcan.org. 



Bladder Cancer Matters podcast host, Rick Bangs

BCAN's Survivor to Survivor Program

Now in our 16th year, BCAN understands that the bladder cancer journey is unlike any other. That feeling of isolation that many patients face, as if they are the only ones in the world on that terrible journey is challenging. Add to that the complexity of bladder cancer diagnoses and it can be overwhelming.

The Bladder Cancer Advocacy Network's "Survivor to Survivor" program connects newly diagnosed bladder cancer patients with trained volunteers who have "been there and done that" and have been through a bladder cancer diagnosis and treatment. BCAN carefully selects and trains volunteers who are then connected with those requesting support.


One of those who volunteers is Jim Piersall. Jim was diagnosed with bladder cancer in early 2013. Jim's doctor performed a TURBT and unfortunately, his results showed T2 muscle invasive bladder cancer. In April of 2013, Jim underwent a radical cystectomy and the surgeon also removed his prostate. This is major surgery and the decision to have one's bladder removed is a very difficult one. To help those in similar situations, Jim now gives back in BCAN's Survivor to Survivor program.

Jim told BCAN: "The Survivor to Survivor program gives me a way to channel my support for men going through what I went through. There is no greater calling than helping another human as they go through this most uncertain time in their lives. If I can lessen their burden and steer them in the direction of positive thinking, good nutrition and enjoying and adjusting to life post cancer, then I have done well."

If you are a newly diagnosed bladder cancer patient looking for someone to talk to, please visit bcan.org/survivor-to-survivor and fill out the online form. You can also contact BCAN by phone at 301-215-9099, extension 212. A member of BCAN's staff will get back with you.



BCAN Volunteer Jim Piersall and Lori Plotke at the BCAN's Palm Beach event in March 2019.

If you have been through a bladder cancer diagnosis and treatment and would like to help others, please contact Morgan Stout at mstout@bcan.org 

There is no greater calling than helping another human as they go through this most uncertain time in their lives."

— Jim Piersall, survivor

Bladder Cancer Events and Programs in 2021

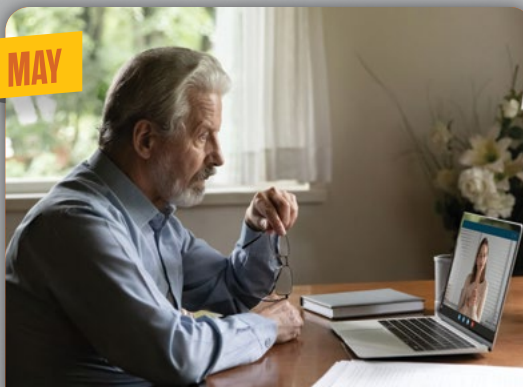
BCAN has a host of exciting and informational activities happening in 2021. You can learn more about each event or program by visiting BCAN's web site at bcan.org.



MAY

Virtual Walk to End Bladder Cancer

BCAN's 2021 Virtual Walk to End Bladder Cancer will be held on May 1, 2021.



MAY

Ask the Experts 2021

Ask the Experts will be held on May 26, 2021. Register at bcan.org/ask.



OCTOBER

Summit for Patients and Families

The Bladder Cancer Summit for Patients and Families will take place in October of 2021.



MAY

Bladder Cancer Awareness Month

BCAN works throughout the month of May to raise awareness of the disease.



ALL YEAR

Patient Insight Webinars

BCAN's popular webinar series brings information to your computer, tablet or smartphone.



ALL YEAR

BLADDER CANCER MATTERS PODCAST

PRESENTED BY BCAN
BLADDER CANCER ADVOCACY NETWORK

"Bladder Cancer Matters" Podcast

Bladder Cancer Matters is a podcast by, for and about the bladder cancer community.



ALL YEAR

Treatment Talks

Live webinars that include expert physicians along with a patient who has undergone that very treatment.



ALL YEAR

Coffee & Conversations

BCAN
Bladder Cancer Advocacy Network

Coffee and Conversations

Online programs that feature presentations by community bladder cancer experts.

May is Bladder Cancer Awareness Month

BLADDER CANCER AWARENESS MONTH MAY 2021

#BladderCancerAware

www.BCAN.org

Each May, Bladder Cancer Awareness Month, BCAN works to elevate the profile of the disease to members of our own community as well as to the general public. Raising awareness of bladder cancer is critical as more than 83,000 people in the United States will be diagnosed in 2021, a 3% increase over the prior year according to the American Cancer Society. Increasing public awareness can improve the quality of life for people with bladder cancer and dramatically enhance the chances of survival. Simply put, increased awareness can save lives.

While COVID-19 has changed the way that we carry out awareness activities during the pandemic, we have not missed a beat and plan a robust and active schedule of events and activities for Bladder Cancer Awareness Month.

Virtual Walk to End Bladder Cancer

We are kicking off Bladder Cancer Awareness Month on May 1 with the Virtual Walk to End Bladder Cancer. Last year's Virtual Walks featured more than 2,100 participants from 46 states, Washington, DC and six countries. This year, we want to do even more.

On May 1, the Virtual Walk will begin at 11:00 am ET with a live broadcast across BCAN social

We'll be kicking off Bladder Cancer Awareness Month activities with the Virtual Walk to End Bladder Cancer on May 1, 2021. For more information, please visit bcanwalk.org.



media channels featuring members of our wonderful community, including patients, caregivers, sponsors, advocates, medical and research professionals and more. We invite you to register using the Walk web site (bcanwalk.org) or the "Walk with BCAN" app.

Registration is free and everyone who raises \$100 or more will receive the 2021 Walk T-shirt.

We hope you will join us!



Our four-legged friends also support our quest to end bladder cancer.

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Walk with BCAN

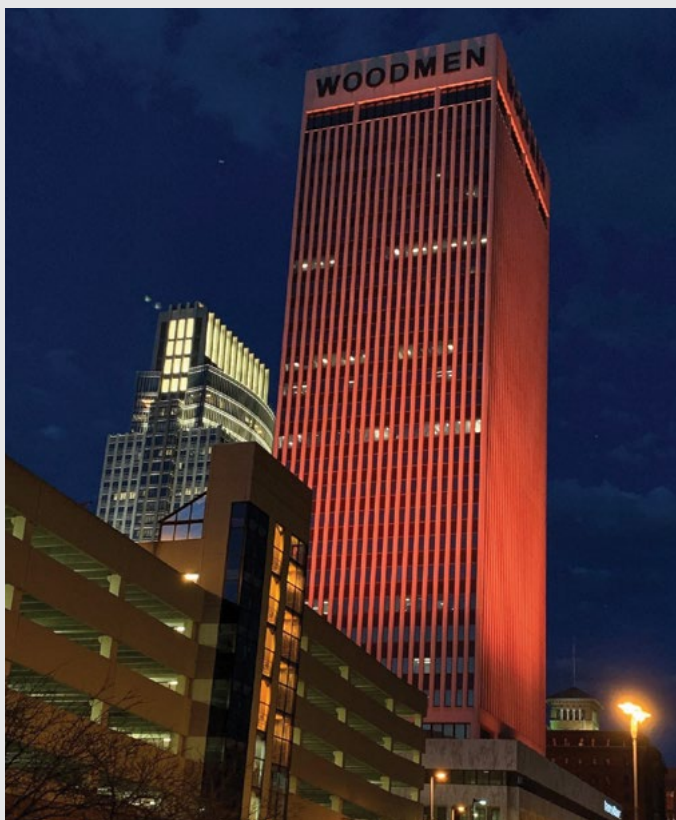
Download our app to send messages and check your fundraising progress on the go from your phone or tablet.



Orange Illuminates the Month of May

Additionally, as we do every year, our wonderful volunteers work with sites and cities across America to illuminate buildings and other locations in orange to raise awareness of bladder cancer. If you are interested in arranging for an illumination in your city, please send an email to communications@bcan.org and we will be delighted to work with you.

We will “see” you all throughout May! 



The WoodmenLife tower in Omaha, Nebraska, illuminated in orange on May 1, 2020.



For seven consecutive years, BCAN's strong financial health and commitment to accountability and transparency earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator.

Only 7% of all charities ranked have scored this high for seven consecutive years and we are proud to be good stewards of our donor's generous contributions.



Support for Bladder Cancer Patients

BCAN's Survivor to Survivor program matches newly diagnosed bladder cancer patients with trained volunteers with similar medical backgrounds. If you are a bladder cancer patient and are looking to talk with someone for support, please send an email to Morgan Stout at mstout@bcan.org.



Treatment Talks

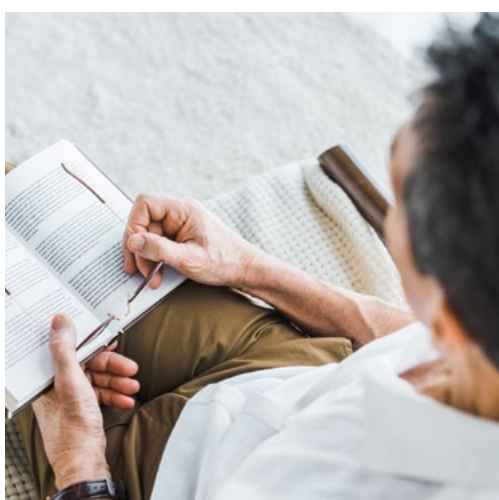
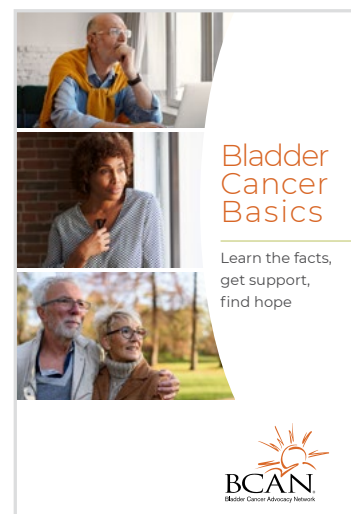
Treatment Talks are webinars that offer two important perspectives about specific bladder cancer treatments. One is a physician who is an expert on a particular type of treatment for bladder cancer. The second perspective comes from patients who have undergone the treatment that they are discussing. To learn more about Treatment Talks and other upcoming BCAN webinars, please visit our site.

www.BCAN.org/webinars

Bladder Cancer Basics for the Newly Diagnosed

The newest edition of BCAN's handbook is available, free of charge, to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. Bladder Cancer Basics contains more than 50 pages about bladder cancer signs, symptoms, diagnosis, treatment and survivorship. *Download your free copy today.*

www.BCAN.org/handbook



The Gift that Keeps on Giving – Monthly

A recurring donation (the same amount donated each month) to BCAN will help us continue our critical work of helping bladder cancer patients and those who love them. For example, a \$50 per month recurring donation will enable us to deliver approximately a hundred copies of our most popular publications to newly diagnosed patients and their families. *Make your recurring monthly donation today.*

www.BCAN.org/donate



MAKE THIS YOUR MOMENT OF GLORY.

WANT TO LEARN MORE?

Anita Parker
Director of Planned Giving
301-215-9099 ext. 202
aparker@bcan.org

Have you already made a gift to us? If so, please tell us about it so we can give you the thanks you deserve! Knowing about your plans allows us to express our appreciation and helps us to prepare for a strong future.

With a legacy gift to Bladder Cancer Advocacy Network you can help us do what we do today, even better, for generations to come.

Simple ways to make your mark on the future:

- ✓ Make a gift through your will or trust
- ✓ Give life insurance you no longer need
- ✓ Donate appreciated stock and saving on taxes
- ✓ Consider a gift of real estate
- ✓ Make a gift that gives you fixed payments for life
- ✓ Make a gift that protects your assets

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Leading the way to awareness and a cure

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BCAN'S ANNUAL WALK TO END BLADDER CANCER **JOIN OUR VIRTUAL WALK IN 2021!**



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



FOR MORE INFORMATION VISIT **BCAN.ORG/WALK** OR CALL **1-888-901-2226**.