

BOARD OF DIRECTORS

Gerald McNamara, *Chair*

Robert Levin, *Treasurer*

Jared Sher, *Secretary*

Jamie Gillespie

Mary Gushée

Beverly James

Cheryl Taylore Lee, MD

Seth Lerner, MD

David Pulver

Neal Shore, MD

David B. Schulman

Diane Zipursky Quale
Co-Founder

STAFF

Andrea Maddox-Smith
Chief Executive Officer

Joslyn Brown
Administrative Assistant

Stephanie Chisolm, PhD
Director of Education & Research

Bernadette Fitzsimmons
Research Coordinator

Anita Parker
Director of Development

Morgan Powell
Education & Outreach Manager

Trenny Stephens
Office Manager

Mark Story
*Director of Communications
and Marketing*

Rebecca Yannopoulos
Senior Walk Manager

COVID-19 and Bladder Cancer: Q&A with Two Doctors on the Front Lines

COVID-19 has impacted millions of people throughout the world and has also added multiple layers of complications for bladder cancer patients.

To get the perspective of bladder cancer experts on the front lines during this crisis, the Bladder Cancer Advocacy Network

(BCAN) recently interviewed urologists Dr. Jonathan Wright of the Urology Center at the University of Washington Medical Center in Seattle; and Dr. Gary Steinberg, Chair of the BCAN Scientific Advisory Board from NYU Langone Health in New York City.

These interviews were conducted in May 2020 and reflect the information that was available at that time.

When did you realize that COVID-19 was going to impact care for bladder cancer patients?

Dr. Wright: With initial COVID-19 outbreaks in a nursing home in our area, because the average age for bladder cancer diagnosis is 72, I knew that this was going to impact our bladder cancer patients right away. COVID-19 then began to impact the way we counsel patients too.

Dr. Steinberg: I got an email at the beginning of March saying that all of our travel and meetings were going to be canceled for March and April. At the time I thought "Oh, it's such overreach and they're overreacting," and it was really not necessary. Well, I could not have been more wrong. Fortunately, we have faculty, staff and an administration that were taking this very, very seriously.

Our last day in the operating room was March 25th; we're still running much lower than our normal capacity for cancer surgery at NYU. We're rolling out slowly. I am now seeing patients in person and via telemedicine and doing TURBTs.

Continues on page 4 >

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...



All of us have watched as COVID-19 spread throughout the United States and the world. As the CEO of BCAN, I watched the news unfold from a variety of perspectives. As I saw how quickly the virus was spreading, I thought about the health and safety of the BCAN staff and their loved ones. At the same time, I also worried about how COVID-19 would impact vulnerable populations within the bladder cancer community.

In mid-March, I made the decision to close BCAN's offices and have our entire staff work from home. I am pleased to say that although we had to adjust quickly, we have not missed a beat. All of the critical work we do for the bladder cancer community has continued. We have found new and innovative ways to connect while we all keep a safe social distance, like our first ever **Virtual**

Walk to End Bladder Cancer that was broadcast live on all of BCAN's social media channels on May 2.

Concerned about how COVID-19 is impacting those with bladder cancer, BCAN convened a panel of bladder cancer experts and an infectious disease doctor who answered questions from our patients. The result of this collaboration was the "COVID-19 and Bladder Cancer FAQ" on our web site, bcan.org/covid-19-faq. We hosted a series of seven webinars featuring experts discussing the regional impact of the pandemic on bladder cancer treatment and surveillance. An additional program featuring a BCAN patient advocate and mindfulness meditation practitioner helped bring live, interactive video information to our wonderful community.

"As COVID-19 spread across the United States, we focused on how it impacts the bladder cancer community. Although we had to adjust quickly, we have not missed a beat."

I realize that no matter how we prepare for or react to the pandemic, this is a tremendously unsettling time for the bladder cancer community. Please know that you are foremost in our thoughts, and foremost in carrying out our mission.

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.

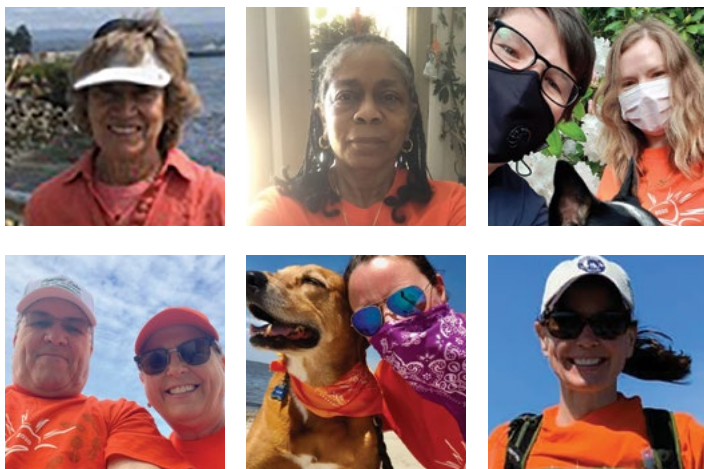
2020 Virtual Walk to End Bladder Cancer

May is Bladder Cancer Awareness Month when the majority of the annual Walks to End Bladder Cancer take place. This year, Walks were scheduled to happen in 27 cities across the United States, then COVID-19 changed everything.

Because of the pandemic, BCAN postponed or rescheduled the in-person Spring Walks. We know that Walks are special and meaningful events for many people in our community. In March, BCAN set out to “make lemonade out of lemons” and planned and launched the 2020 Virtual Walk to End Bladder Cancer.

As the Virtual Walk was being planned by BCAN, the Walk committee and Walk ambassadors, all knew that it was imperative to capture the energy and enthusiasm from the in-person Walks and translate them to a virtual event. BCAN collected short video segments from more than 35 bladder cancer patients, survivors, caregivers, advocates, sponsors, medical professionals, BCAN staff and many more. One bladder cancer patient and the son of a survivor donated their time and energy to record music to accompany segments within the broadcast.

The end result was a vibrant and engaging video broadcast on May 2 that featured members of our BCAN community. Each person provided their own special message about why they chose to participate in the Virtual Walk.



Lisa Gray & Matthew Lee walking to honor Matthew Lee

The results were amazing, fueled by so many caring and involved people. The Virtual Walk drew:

- 1,742 participants
- 213 teams
- 46 states + DC
- 6 countries
- 3,700 viewers
- Nine national and 13 local sponsors.

Equally amazing was the level of interaction across BCAN Facebook, Twitter and YouTube channels where the event was broadcast live. Hundreds of people posted supportive comments, pictures and videos of themselves joining together while maintaining social distancing, as well as supporting each other in their own bladder cancer journeys.

All of us at BCAN would like to say “thank you” to the Walk committee as well as the thousands of participants, viewers and supporters who helped make this virtual event such a success, especially in such a challenging year.

It's not too late to participate virtually. We are planning a Fall Virtual Walk on Saturday, October 3, 2020. Visit bcanwalk.org to register. You can also join our Virtual Walk Facebook page at facebook.com/groups/BCANwalk.

In your practice, are you seeing bladder cancer patients as being any more susceptible or at a higher risk of contracting COVID-19?

Dr. Wright: The greater risk would apply to those who are immediately post-surgery, like a cystectomy or who are getting active chemotherapy and are immunosuppressed. I think the average bladder cancer patient with non-muscle invasive bladder cancer or NMIBC, who is getting intravesical therapy or just getting surveillance is at no higher risk than the average person.

“One of our major challenges is to help the patient population understand when it is safe to come back for evaluations.”

Dr. Steinberg: The scientific literature and the information from the American Society of Clinical Oncologists clearly demonstrates that cancer patients and those receiving chemotherapy are at higher risk for COVID-19 infections and complications. We have to balance that. There are also questions about immunotherapy. Should we be treating patients with immunotherapy?

One of our major challenges is to help the patient population understand when it is safe to come back for evaluations, surveillance and treatment. There is no question that hand washing, hygiene, and social distancing are critically important. The hospitals in New York have really taken it to heart. I've never seen such sparkling clean hospitals in my entire life.

Is your facility altering treatment schedules or are patients still coming in?

Dr. Wright: For the low risk non-muscle invasive bladder cancer patients, surveillance cystoscopies have been delayed. That is a tough thing for anyone to hear, even though it's a lower risk. It's hard to tell them, “We're not going to be checking on you for a little while.” We have not altered treatment of high risk patients who are receiving BCG. Of course, we

are in the middle of a global BCG shortage as well. Independent of that, we have kept our BCG treatments going for the high-risk patients. For the intermediate and high-risk non-muscle invasive patients who aren't on BCG, we've had to carefully consider extending their surveillance cystoscopy schedule.

If a bladder cancer patient is a year and a half after diagnosis and treatment, we might say, “Okay, you haven't had a recurrence for a while, let's push your next cystoscopy out a little bit.” I think BCG raises another concern because some of the side effects of BCG might be the same ones that prompt someone to go in and say, “Do I have COVID? Am I having fever? Am I having muscle aches?” Those are things that a significant proportion of BCG patients may notice after they have their treatment. How do you sort that out?

Dr. Steinberg: At NYU we have been very selective in how we use our BCG.

I will tell you that there are a certain number of patients who delayed starting their intravesical therapy and have delayed or missed their maintenance therapy. There are some patients that haven't even started their intravesical therapy yet, even though we initially wanted to do that starting in March.



What would you tell lower risk bladder cancer NMIBC patients about delaying tests or surveillance or even BCG treatment?

Dr. Wright: I talk to them about balancing risks and benefits. We do know that if we space out the intervals for cystoscopy in lower risk patients, delaying is very unlikely

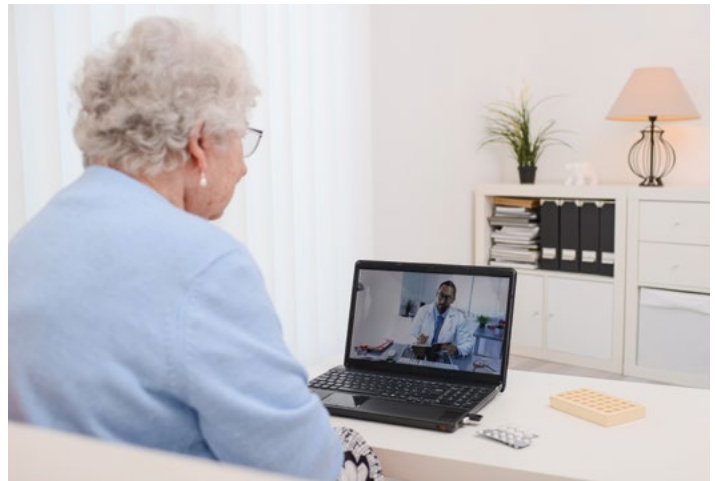
to impact their overall survival or trajectory with the cancer. I wouldn't want patients coming in and potentially putting themselves at risk of catching a disease that could be life threatening. I will often tell them that if they were my mother or my father, I would tell them, "Stay home. Let's wait another six to eight weeks before we do your next cystoscopy."

Dr. Steinberg: I think it depends on the grade and the stage of the tumor and where they are in their treatment. We do have some wiggle room, for example, even in high-risk non-muscle invasive bladder cancer, or NMIBC. We've got about a 12 to 24-month window to truly figure out where the disease process is going.

Muscle invasive bladder cancer is much different. We know that untreated muscle invasive disease will cause metastasis and death in a 12 to 18-month period in the majority of patients. So, yes, can we delay a month? I think so. Can we delay two months? Maybe. But once we start delaying beyond that, we really run the risk of adverse outcomes from the cancer. So, it is something we decide on a case-by-case basis and we cannot just say, "Well, we'll wait for six months." That, clearly, is very detrimental.

How have day to day operations changed at your hospital since COVID-19?

Dr. Wright: I think the biggest thing for us has been the explosion of telemedicine. Literally overnight, telemedicine became a routine part of our practice. We were lucky in that Dr. John Gore, who is very involved with the Bladder Cancer Advocacy Network, was doing a pilot study looking at offering telemedicine for patients who are hundreds of miles away from Seattle, because we often see patients from about five different states. It costs a lot of money to fly from Montana, Wyoming or Alaska. Dr. Gore was trying to see if he could identify the cost savings and help the insurance payers to realize this and approve more telemedicine. We were at least somewhat set up so we could actually activate telemedicine immediately. There is also the issue of managing the fear and uncertainty that we all had of going into



work. Although we may not be working on a COVID unit, people have concerns of going to a hospital-based clinic where patients who are coming in are potentially sick."

Plus, the rules or the guidelines were changing almost daily related to what kind of screening had to take place. And now of course we're wearing masks for everything. COVID-19 has really forced everyone to be patient and flexible with the dynamic nature of it and forced us to work with our own fears and concerns, too.

Dr. Steinberg: Every expert you hear from throughout the entire world is saying: testing, testing, testing. All of the faculty at NYU are COVID-19 tested as are patients going to the cancer center to get treatments. All of our patients coming for surgery are being tested. I think that we need to continue to test and we need to also figure out tracking as well.

What is the one thing related to COVID-19 and bladder cancer that you tell your patients?

Dr. Wright: I would say it's two things. The first one is to continue to do all of the things to protect yourself: wash your hands, avoid touching your face, and practice social distancing — all of the things that you can do to protect yourself against COVID, you need to continue to do.

At the same time, none of these precautions are "Don't go see your doctor," or, "Don't manage your cancer or your other medical problems." Work with your urologist or your

Continues page 8 >

2020 Virtual Walk to End

BY THE NUMBERS

1,742 participants

213 teams

46 states + DC

6 countries

3,700 viewers

TOP FUNDRAISERS

1. Dave Dimick
(New York City)

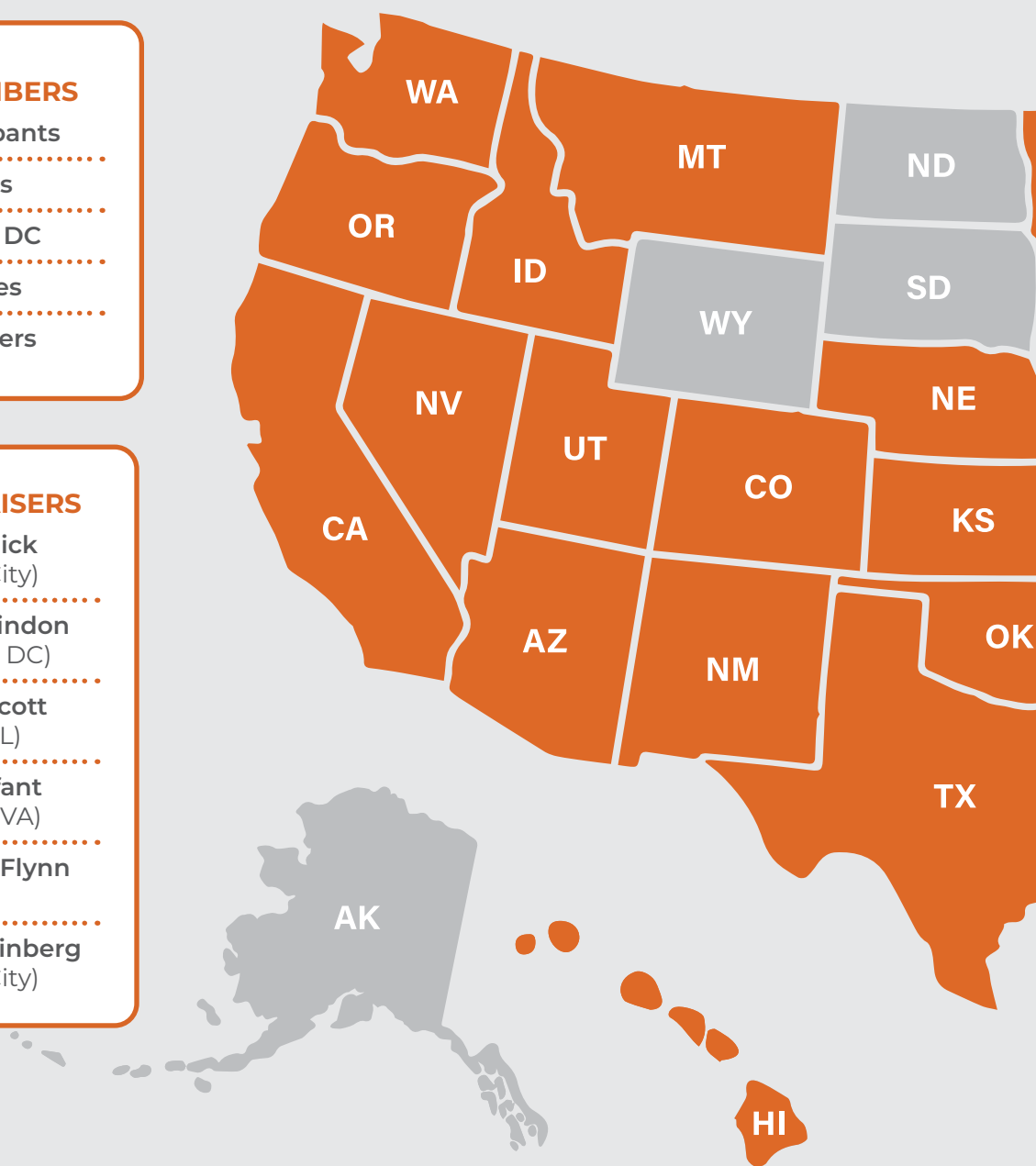
2. Megan McLindon
(Washington DC)

3. Mary Prescott
(Chicago, IL)

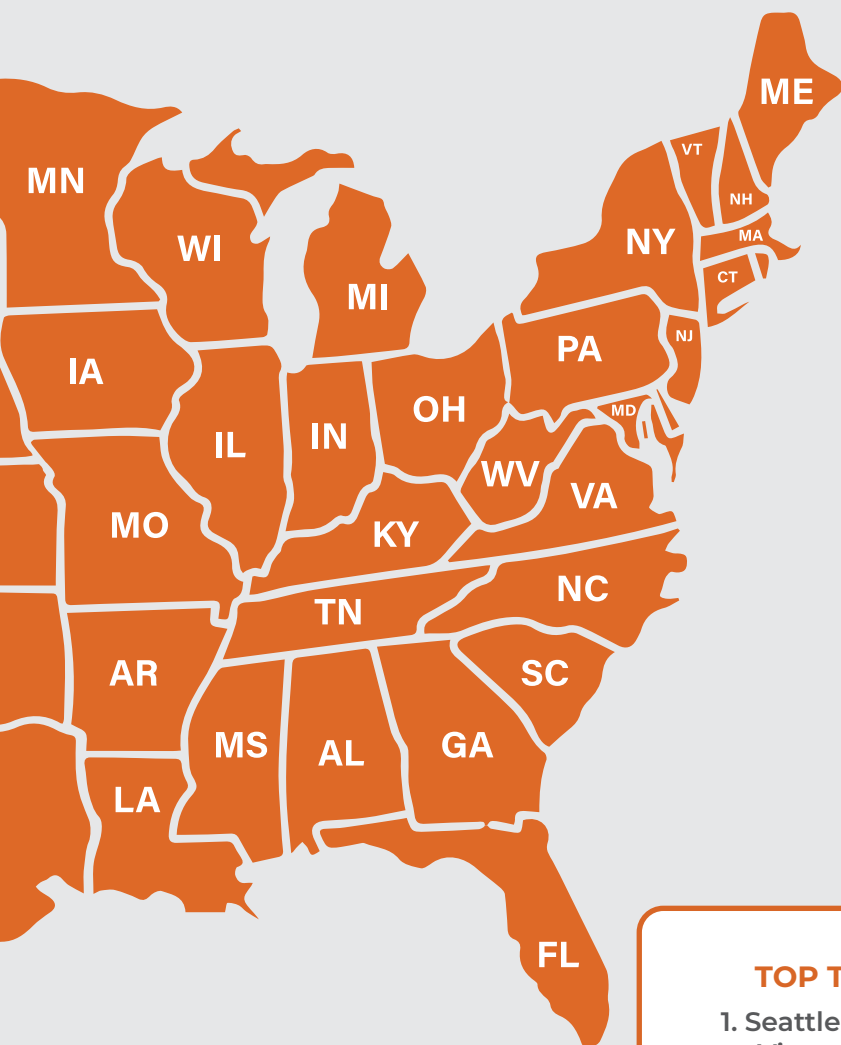
4. Rick Bulifant
(Richmond, VA)

5. (tie) Jessica Flynn
(Virtual)

5. (tie) Gary Steinberg
(New York City)



Bladder Cancer Highlights



NATIONAL SPONSORS



LEADERSHIP SPONSORS

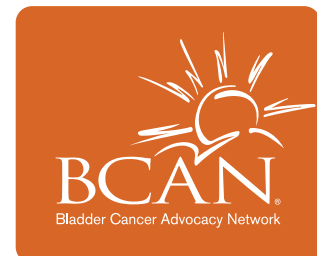


PATRON SPONSORS



TOP TEAMS

1. Seattle Genetics Virtual Team
2. Reynolds Strong (Long Island, NY)
3. TEAM MCLINDON (Washington DC)
4. FerGene (Virtual Walk)
5. Brave for Dave (New York City)



**VIRTUAL WALK
TO END BLADDER CANCER**

NO ONE WALKS ALONE


“Bladder cancer doesn’t stop because of COVID, they happen together and we need to work together to figure out how we manage those two, and we can.”

team to help figure out how to balance those two. Bladder cancer doesn’t stop because of COVID, they happen together and we need to work together to figure out how we manage those two, and we can. Protect yourself from COVID, while we also help protect you from progression of your cancer.

Dr. Steinberg: I think the message is that this is a new normal for at least the next two to three years. We need to all practice universal precautions. The healthcare profession has risen to the occasion and the pharmaceutical industry has risen to the occasion, and that we are thinking long and hard on how we can



Dr. Badar Mian and staff, Albany, NY.

minimize the risk of COVID-19. But bladder cancer is a life-threatening condition and we can guarantee that, especially high-grade bladder cancer, will cause significant complications and potential loss of life if it’s not managed and treated. Bladder cancer is a serious disease that we need to continue to treat seriously. 



**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

888-901-BCAN x 202

BCAN Continues Our Critical Mission

Like thousands of other businesses across America and in light of the COVID-19 pandemic, last March, the Bladder Cancer Advocacy Network (BCAN) made the decision to have all staff work remotely. With a flexible work environment and good technology, we have continued to serve the bladder cancer community. In fact, the picture below is of the BCAN team during a recent staff “meeting” that was conducted online. Just as before, we are continuing our critical mission of providing educational resources, advancing bladder cancer research and supporting those impacted by the disease.

As always, we will be responsive. Listed below are the names, titles and email addresses of our staff members. Please feel free to reach out to any of us. If you prefer to call our offices (301-215-9099), please either leave a message in our general mailbox, or and hit the # key for a directory of staff names. ❶

Andrea Maddox-Smith,
CEO

amsmith@bcan.org

Joslyn Brown,
Administrative Assistant

jbrown@bcan.org

Stephanie Chisolm, Ph.D.,
Director of Education
and Research

schisolm@bcan.org

Bernadette Fitzsimmons,
Research Grants
Coordinator

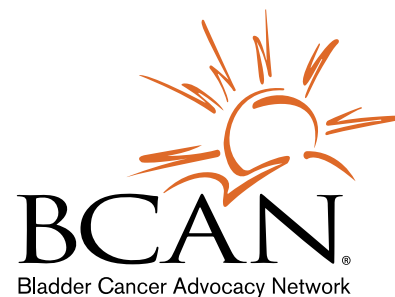
bfitzsimmons@bcan.org

Anita Parker, Director
of Development

aparker@bcan.org

Morgan Powell, Outreach
and Education Manager

mpowell@bcan.org



Trenny Stephens,
Office Manager

tstephens@bcan.org

Mark Story, Director
of Communications
and Marketing

mstory@bcan.org

Rebecca Yannopoulos,
Senior Walk Manager

ryannopoulos@bcan.org



Why Patients and Caregivers Share Their Bladder Cancer Stories

One of the most popular sections on the BCAN web site is “Bladder Cancer Stories.” In it, real patients and caregivers share their experiences about how bladder cancer has impacted them and also many of the difficult and critical decisions that they had to make. The stories are real and gripping. Here, we’ve highlighted just two of the many stories from bcan.org: Camille’s and Ralph’s bladder cancer stories.



In her story, Camille shared:

“I was diagnosed in January 2015. It was one serious year, one of the biggest for our family, there was a lot going on. I had knee surgery in May. I was tired and wasn’t rehabbing

my knee well at all. My physical therapist didn’t understand why I wasn’t trying. I didn’t understand why I wasn’t trying. I just didn’t care and felt crappy.

“I was just as a typical person living a typical life. I just didn’t know what was up with me. After several misdiagnoses, my urologist told me ‘It’s a tumor and it’s sizable.’”

Camille felt overwhelmed with her diagnosis and the choices she had to make:

“Trying to figure out what to do, that’s how I found BCAN. I didn’t anticipate how big that surgery was going to be because it was the full hysterectomy and cystectomy. When I talk to people now, I don’t want to scare them, but always want to tell them to not underestimate the surgery.”

Why did Camille want to share her story? She wants to help others.

“I realized that now that I’ve pushed all the way through the past three and a half years with bladder cancer, I am now at a point where I can help other people.”




When Ralph was diagnosed with bladder cancer, he was stunned.

“Like many bladder cancer patients, I was shocked when a urologist gave me the diagnosis. Cancer wasn’t for me; it was for

other people. And bladder cancer? I didn’t know anything about it, but some quick research confirmed I had no obvious risk factors. All moot, though. My wife Eva and I needed quickly to come to grips with the next steps to save my life—if not my bladder.

Why did Ralph choose to share his bladder cancer story? Like many patients, he was faced with a difficult decision of opting for a neobladder, a complex operation, or electing to have an ileal conduit, constructed from a section of the intestine to transport the urine to the outside surface of the abdomen. Ralph told BCAN:

“My purpose in sharing my story is neither to promote the neobladder option nor to present assurances that complications will never occur with whichever diversion someone selects. I simply wish to emphasize the importance of an optimistic outlook. Step by step, you will make the decisions you need to make, you will do your rehab, you will participate actively in your treatment, and you will grab every opportunity to resume a normal, productive life.”

You can read more bladder cancer stories from real patients and caregivers on the BCAN web site at bcan.org/my-bladder-cancer-stories. You can also sign up to share your own story. 

Bladder Cancer Basics and Tips for Caregivers

The Bladder Cancer Advocacy Network, or BCAN, knows that many bladder cancer patients do not walk that journey alone and they have family and friends who care about them and want to help. For 15 years, BCAN has served bladder cancer patients, caregivers and survivors nationwide. Our signature *Bladder Cancer Basics* handbook was updated in 2020 to include all the new treatments that have been approved by the Food and Drug Administration (FDA). Now for the first time, BCAN is proud to announce a new resource, *Tips for Caregivers*, to help the family and friends of those who are diagnosed with bladder cancer. You can order your free copy at www.bcan.org/handbook.


With more than 80,000 people expected to learn they have bladder cancer this year, we know that there are many unpaid caregivers helping them to manage their medical appointments, treatments and even their “new normal” lives after treatment. Caregivers have multiple roles when a loved one has bladder cancer, and it can be a full-time job. It can also be a rewarding and sometimes difficult journey.

Former First Lady Rosalynn Carter said, “There are only four kinds of people in the world: those who have been caregivers; those who are currently caregivers; those who will be caregivers, and those who will need a caregiver.”

As a caregiver, you are a vital part of the patient care team. What happens at home is just as important as what happens at the doctor’s office. With the help of our volunteer Carer Committee, BCAN gathered the information in this booklet to support you as you care for someone with bladder cancer. We created the new *Tips for Caregivers* handbook to provide



“When my wife was diagnosed, I went into Superman mode trying to take care of everything at once. I tried to stay strong and do everything myself. What I should have done was let people help us when they offered.” — John

helpful tools and resources to navigate this challenging journey. Our objective is to increase a caregiver’s understanding of significant topics concerning the diagnosis, treatment and quality of life issues related to bladder cancer and to educate caregivers as patient advocates and to empower them to be more fully equipped to care for their loved ones. Special thanks to the volunteers who contributed to the development of this important resource. Order your copy today at bcan.org/handbook. 



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

4520 East West Highway, Suite 610
Bethesda, MD 20814

Non-Profit
US Postage
PAID
Suburban, MD
Permit #4297

www.BCAN.org/donate

Make your recurring monthly donation today.

and the families.

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. A \$50 per month recurring donation will enable us to deliver three copies of our most popular publications to newly diagnosed patients

The Gift that Keeps on Giving – Monthly



www.BCAN.org/handbook

Download your free copy today.

The newest edition of BCAN's handbook is now 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.

Bladder Cancer Basics for the Newly Diagnosed

