

Bladder Cancer Advocacy Network Newsletter

THE BEACON | SUMMER 2023 | BCAN.ORG



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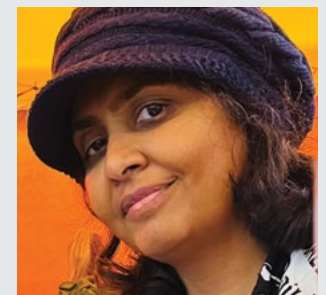
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Shoba's Story: A Kidney Transplant then Three Different Cancers, Including Bladder Cancer

Shoba, a bladder cancer survivor, recently shared her journey with BCAN, describing the challenges she faced and the lessons she learned along the way. Her initial symptom was blood in her urine, which led her to seek immediate medical attention. Despite assuming it was a urinary tract infection, further examination revealed a diagnosis of upper tract transitional cell carcinoma (TCC). TCC affects the cells lining the urinary system, including the bladder, ureters, and renal pelvis.



Shoba R.

To treat the TCC, Shoba underwent a procedure to remove her kidney and ureter, followed by chemotherapy. However, due to her previous kidney transplant, the doctors carefully monitored her kidney function, and eventually adjusted her treatment to carboplatin and Gemzar (Gemcitabine).

Her Second Cancer Diagnosis

After recovering from TCC, Shoba faced another challenge when she was diagnosed with bladder cancer during a routine cystoscopy. The tumor, measuring one centimeter, was promptly removed through a transurethral resection of bladder tumor (TURBT). Subsequently, she received intravesical chemotherapy using mitomycin, as she was ineligible for BCG treatment due to her need for immune suppression.

A few years later, during routine follow-up MRIs, doctors discovered a small lesion in Shoba's liver. Initially, there was concern that the bladder cancer had metastasized. Without conducting a biopsy, the medical team decided to surgically remove the lesion. The pathology report confirmed it to be angiosarcoma, a rare and aggressive cancer originating from the blood vessels within the liver. Shoba underwent chemotherapy once again to combat the angiosarcoma.

Throughout her multiple cancer diagnoses, Shoba faced moments of uncertainty and questioned why she was enduring these challenges. She explained that these emotions are common among patients. Shoba shared her realization that the cause of her cancers may have been linked to her

[Continues on page 3 >](#)

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...



I love our summer newsletter because it enables me to tell you about the amazing, recently completed events that happened in May, Bladder Cancer Awareness Month. It was 31 days full of energy, enthusiasm and compassion.

BCAN hosted our signature Walks to End Bladder Cancer in 14 cities around the United States, and hundreds of individuals who did not have a Walk near them participated virtually. With our army of committed Walk organizers, team captains, volunteers and walkers, BCAN raised more than \$800,000 to help us continue to provide always-free educational programs and support services for bladder cancer patients and those who love them.

Also, this past May, BCAN's Director of Research, Rebecca Johnson, hosted our Annual Ask the Experts event, an interactive discussion on bladder cancer diagnosis and treatment, featuring Dr. Philip Abbosh from Fox Chase Cancer Center in Philadelphia and Dr. Tracy Rose, an Associate Professor of Medicine at the University of North Carolina School of Medicine. These two experts provided valuable insights into the current state and future prospects of bladder cancer management, treatment and survivorship.

I am excited that for the first time ever, we are going to hold a **second** Summit for Patients and Families in 2023 – our spring Summit was held in Phoenix in March. It will take place on October 27 and 28 in Nashville, Tennessee, otherwise known as "Music City, USA." I can't wait to reconnect with our BCAN family and see many of you in person.

As always, I love hearing from you. If you have questions, comments or other thoughts, please feel free to contact me via email at amsmith@bcan.org or by phone at 301-215-9099, extension 201.

Sincerely,

Andrea Maddox-Smith
Chief Executive Officer



My Bladder Cancer Story

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

bcan.org/stories



Women



Young Adults



Caregivers



Men



childhood use of the Aristolochia Indica herb, which is suspected to be a carcinogen and nephrotoxic.

Despite the difficulties she faced, Shoba maintained a positive outlook. She acknowledged the insignificance of her existence in the grand scheme of the universe, finding solace in the understanding that life and death are natural processes.

As an engineer, she approached her situation logically, focusing on what she could do to keep herself alive.


Shoba expressed immense gratitude for the support she received from her husband, Suresh, who stood by her side throughout the journey. She emphasized the importance of having someone in one's corner, such as a spouse, family, or close friends, to provide invaluable support.

Reflecting on her experience, Shoba offered several pieces of advice to fellow bladder cancer patients. First and foremost, she encouraged patients to seek

support and surround themselves with a reliable support system. Additionally, she stressed the significance of being proactive and seeking second opinions to fully understand the treatment options available.

Shoba also emphasized the importance of not letting cancer define one's identity and recommended living life to the fullest while fighting the disease. She encouraged patients to make a plan, understand their cancer and treatment options, and maintain a positive outlook throughout the process.

Shoba spoke highly of BCAN and its impact on the bladder cancer community. She acknowledged BCAN's growth over the years, noting the organization's annual Walks to End Bladder Cancer and its informative podcast. Shoba praised BCAN for providing a platform for survivors to share their stories, inspiring and instilling hope in others facing similar challenges.

Shoba's book, "My Race Against Death" is available on Amazon. 



Scan this QR code to read more patient and caregiver stories

Survivor to Survivor

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

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

If you are a bladder cancer patient and would like to be matched with a survivor, please visit bcan.org/S2S and fill out the online form. You can also call **301-215-9099, extension 212** and leave a message.

For nine 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 nine consecutive years and we are proud to be good stewards of our donors' generous contributions.

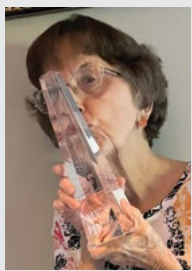
Charity Navigator



◆ FOUR-STAR ◆

Nancy Parrish Honored as the 2023 Beacon of Hope Awardee


At BCAN, we strive to create a supportive community that brings solace to patients, caregivers, and loved ones on their bladder cancer journeys. In celebration of Bladder Cancer Awareness Month, we asked our community to share stories of individuals who have served as beacons of light and hope during their battle against this disease. Out of over 80 nominations, three exceptional finalists emerged, and the BCAN community cast their votes to determine the winner of the prestigious Beacon of Hope award.



Nancy Parrish

We are delighted to announce that Nancy Parrish has been named the recipient of the 2023 Beacon of Hope Award. Nancy, a bladder cancer survivor and remarkable patient advocate, has made a significant impact through her efforts as the organizer of the North Carolina Bladder Cancer retreat. Her selfless

dedication to others is truly inspiring. Nancy sells painted rocks and utilizes the proceeds to defray the costs for those attending the retreat. As one nominator put it, "She is a bladder cancer survivor herself. Her dedication and love for others is evident from the moment you meet her! She paints and sells rocks to help raise money so that registration for the retreat can cost as little as possible for attendees. You are a stranger only once when you meet Nancy. From then on, you are a friend!"

Alongside Nancy, we would like to recognize the outstanding achievements of our two runners-up. Brian Billings, a bladder cancer survivor and passionate patient advocate, has made significant contributions to raising awareness and supporting fellow patients. Additionally, Dr. Amy Luckenbaugh, Assistant Professor in the Department of Urology and a surgeon at Vanderbilt University Medical Center, has demonstrated remarkable dedication to bladder cancer patients through her clinical work and research. 

It's Not Too Early to Plan for a 2024 Walk to End Bladder Cancer


We invite you to join us and thousands of others to walk and help end bladder cancer in the Spring of 2024. This Walk season is going to be our biggest and best ever. The Walk registration site will be open as of October 1, 2023 at bcanwalk.org.

Why walk? More than 82,000 people are expected to be diagnosed with bladder cancer in 2023 and it is estimated that there are more than 790,000 people living with bladder cancer in the United States. That's more than the population of four U.S. states.

Join us to support the patient, caregiver, research and medical professional heroes confronting this terrible disease. Register and start now! The earlier you sign up, the more money you can raise to help patients and loved ones.

Be sure to count your steps and fundraise using our Walk with BCAN mobile app. Get it in the Apple Store or Google Play.

Back by popular demand, this year we will again be offering amazing incentive prizes for raising money to help bladder cancer patients.

Thank you so much for everything you do to help BCAN create more and better tomorrows for bladder cancer patients and loved ones. 



Scan this code to register after October 1, 2023



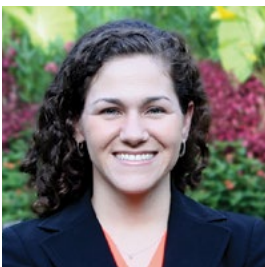
BCAN Empowers the Next Generation of Bladder Cancer Researchers

During Bladder Cancer Awareness Month in May 2023, BCAN proudly announced the recipients of its prestigious Young Investigator Awards. These coveted awards aim to foster the growth and development of promising early career scientists and clinical researchers dedicated to advancing the understanding and treatment of bladder cancer. Among numerous exceptional entries, five outstanding individuals were selected as the 2023 awardees.

Each Young Investigator Award provides a grant of \$75,000, supporting one year of groundbreaking bladder cancer research. BCAN was thrilled to present the 2023 Young Investigator Awards to the following remarkable individuals:



Dr. Jonathan Chou, MD, PhD, Assistant Professor of Medicine, Hematology/Oncology at the University of California, San Francisco



Dr. Kathryn Gessner, MD, PhD, Postdoctoral Fellow in Urologic Oncology at the University of North Carolina at Chapel Hill



Dr. Sean Clark-Garvey, MD, MPH, Postdoctoral Fellow in Medical Oncology at the University of North Carolina at Chapel Hill




Dr. Soonbum Park, PhD, Postdoctoral Research Scientist in Molecular Pharmacology and Therapeutics at Columbia University Medical Center

In addition, BCAN awarded the Patient-Centered Clinical Research Young Investigator Award to:



Dr. Rishi Sekar, MD, Postdoctoral Fellow and Clinical Instructor in Urologic Oncology at the University of Michigan

Andrea Maddox-Smith, our CEO, expressed her enthusiasm for these awards, stating, “Today’s early-career bladder cancer investigators often emerge as leaders in their respective fields. We are thrilled to invest in their careers, knowing they will contribute significantly to improving the lives of bladder cancer patients and their loved ones. None of this would be possible without the generosity of our donors, to whom we are immensely grateful.”

By nurturing and supporting the next generation of bladder cancer researchers, BCAN continues to make strides in advancing knowledge, treatment options, and ultimately, the well-being of bladder cancer patients. The organization remains dedicated to its mission of fostering breakthroughs in bladder cancer research and offering hope to those impacted by this disease. 

2022 Walk to End Bla

BY THE NUMBERS

Total Number of Walkers: 2,401

Total Number of Teams: 236

TOP FUNDRAISERS

Sepehr Egrari

Adrien Bernstein

Jeff Epstein

Kendra Froehlich

Megan McLindon

TOP FUNDRAISING TEAMS

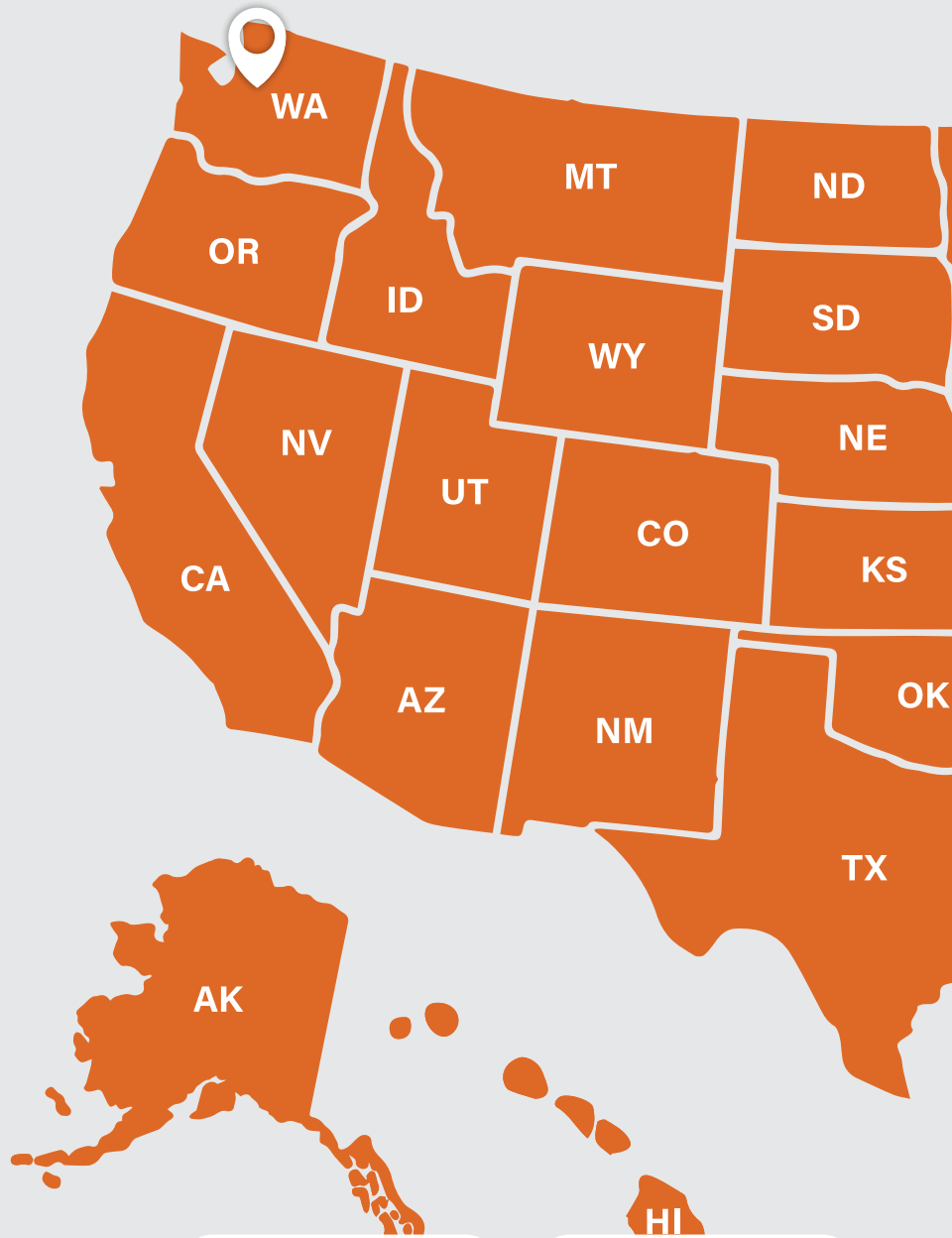
Brave for Dave

UCSF Bladder Heroes -
How Riley Can you Be?

UCSD Tumor Terminators

Team Egrari

Team Seagen



VIRTUAL

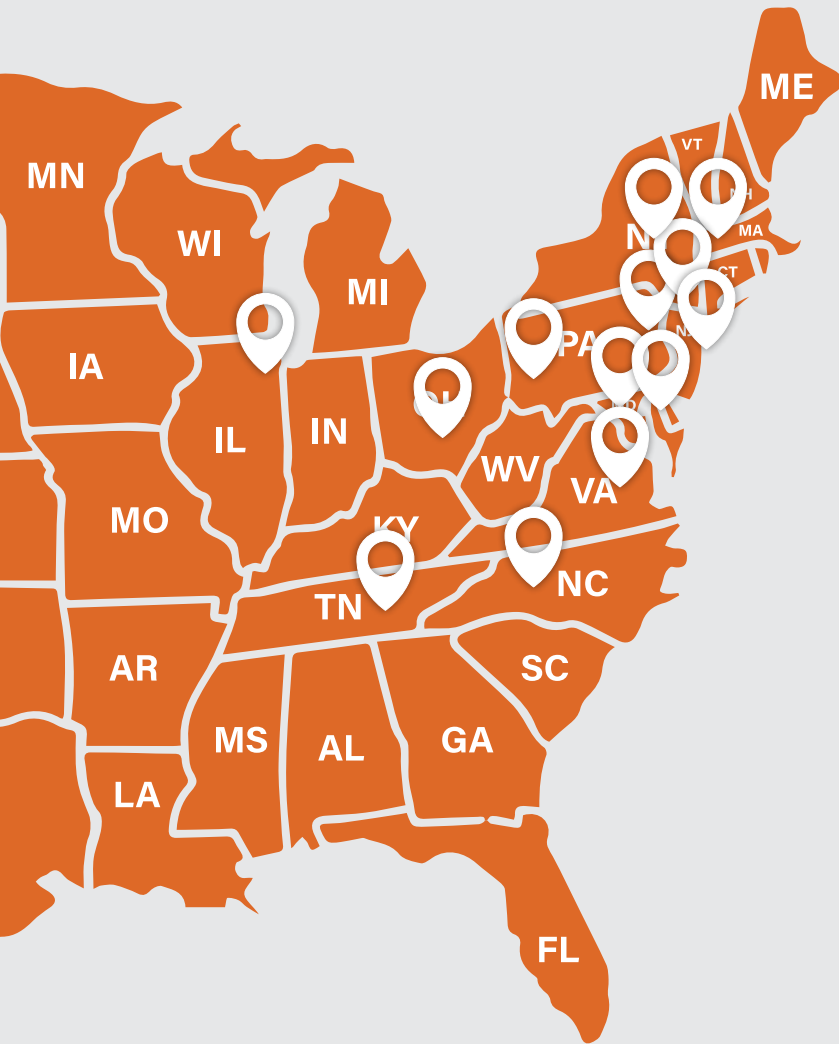


ALBANY



BALTIMORE

Bladder Cancer Highlights



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**WALK TO END
BLADDER CANCER**

NO ONE WALKS ALONE



BOSTON



SEATTLE



WASHINGTON DC

Bladder Cancer Awareness Month 2023

What a month!

We can't believe how fast the 2023 Bladder Cancer Awareness Month flew by! It has been an exhilarating and rewarding journey. May was bursting with energy and enthusiasm, and we're thrilled to share all the fantastic highlights with you.

We learned

Throughout May, our focus was on educating and raising awareness about different types of bladder cancer. Each week, we delved into a specific disease state, providing valuable information on treatment options, and we also offered patient stories, videos, podcasts, webinars, and much more. This included:

- Non-muscle invasive bladder cancer (May 2-8)
- Muscle invasive bladder cancer (May 9 – 15)
- Advanced or metastatic bladder cancer (May 16 – 22)
- Upper tract urothelial carcinoma (May 23 – 29)

We walked

May was not only about knowledge and awareness; we also had the privilege of organizing the Walks to End Bladder Cancer in 14 incredible cities. And let's not forget our Virtual Walk to End Bladder Cancer, which was a smashing success! If you missed the live broadcast, no worries.

Scan the QR code to the right to watch the Virtual Walk broadcast to experience the excitement! Check out our centerfold in this newsletter to read more.



Scan to watch the broadcast

We asked

Our annual Ask the Experts live event was an exceptional opportunity for everyone in our community. We were fortunate to have two leading bladder cancer doctors in the United States answering your important questions about the disease. Don't miss out! Watch the video to the right to gain valuable insights from two amazing experts.




Scan to watch Ask the Experts

We celebrated

Last but certainly not least, we celebrated the indomitable spirit of our community by voting for a 2023 Beacon of Hope finalist. Nancy Parrish emerged as the winner, an extraordinary individual whose work has inspired us all. You can learn more about Nancy and her incredible work as well as the two other finalists on page 4.

We give thanks

On behalf of the entire Bladder Cancer Advocacy Network, we want to express our heartfelt gratitude for your unwavering support. Our vibrant, caring, and compassionate BCAN community is the driving force behind our mission to end bladder cancer. Although Bladder Cancer Awareness Month has ended, our essential work continues — thanks to you! 



MAKE THIS YOUR MOMENT OF GLORY.

WANT TO LEARN MORE?

Bladder Cancer Advocacy Network
Planned Giving
development@bcan.org
301-215-9099

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

[BCAN.PLANNEDGIVING.ORG](https://www.bcan.org/plannedgiving)



Secure Your Family's Future with a Free Will

Did you know that a considerable number of Americans do not have a Will? Despite the importance of this legal document, many individuals delay creating one due to concerns about the process being unsettling, expensive, or complicated. However, preparing a Will can be a meaningful way to support your loved ones and the causes you care about. That's why we have partnered with FreeWill, an organization that offers a simple and free online solution for creating your own Will.


Creating your Will is easier than you may think:

1. Begin the process by visiting bcan.org/FreeWill.
2. Follow the step-by-step instructions to provide the necessary information for your Will. You'll be asked a few straightforward questions about yourself and your wishes.
3. Once completed, you can print out the documents. FreeWill transforms the information you provide into precise legal language and presents it as a printable document. This PDF will include state-specific instructions to guide you through the signing process and ensure the document's validity.
4. Sign the documents and keep them in a safe location. Once you print out your Will and sign it in the presence of two witnesses, it becomes a legally binding document.

FREEWILL

We understand that online Will creation may not be suitable for everyone. In such cases, FreeWill offers a searchable database of estate attorneys approved by the American Bar Association. Additionally, FreeWill provides a convenient summary of your responses that you can print and bring to your attorney, saving you time during your consultation.

To get started with creating your Will, please visit bcan.org/FreeWill. If you have any questions about including BCAN in your Will, our Development staff is here to assist you. You can reach them via email at development@bcan.org or by phone at 301-215-9099.

Secure your future and exercise your free will by creating your Will today. Don't leave the important decisions to chance—plan ahead to protect your loved ones and make a lasting impact on the causes that matter to you. 



Bladder Cancer Support Line

- Professional oncology social workers
- Psychosocial support
- Free resources for patients, loved ones and the bereaved

Call now: **833-275-4222**

You are Invited! Fall 2023 Summit for Bladder Cancer Patients and Families

We are excited to let you know that our annual Bladder Cancer Summit for Patients and Families will be held in “Music City, USA” (Nashville, TN) on Friday, October 27, and Saturday, October 28. The Summit will assist you and your family in navigating the path from diagnosis through treatment and on to surveillance and survivorship. Consider your alternatives for detours, choose the shortcuts, and watch out for potholes. Bring your soundtrack, turn on “Survivor-town, USA” on your GPS, and let’s head out on the road to a life free of bladder cancer.

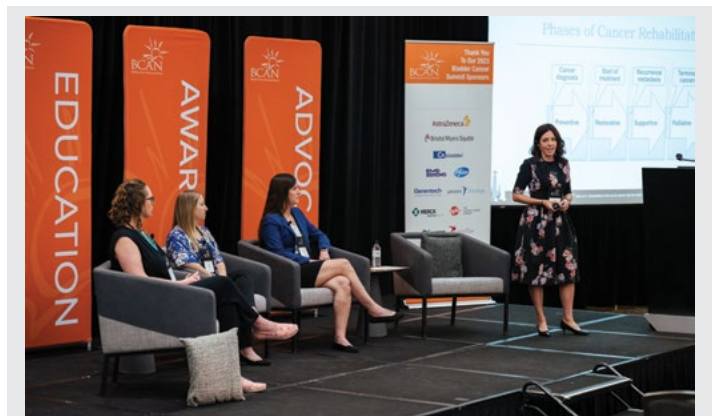
During this Summit, we’ll be talking about:

- How cancer rehabilitation can help you before and after treatment or while managing possible side effects
- The history, value and impact of patient-reported outcomes in guiding future bladder cancer journeys
- Tips for managing disruptions and anxiety from bladder cancer
- Tips and tricks for navigating the road to survivorship
- How physical, mental, and emotional “exercise” can impact your treatment, mental health, and quality of life.

You’ll also hear about exciting new treatments and promising research to diagnose and treat bladder cancer with medical oncologist Benjamin Miron, MD from Fox Chase Cancer Center and Vanderbilt Cancer Center urologist Amy N. Luckenbaugh, MD.



The Summit is free to attend but registration is required. Save your spot by registering at [bcan.org/summitfall23](https://www.bcan.org/summitfall23) or by scanning in the QR code to the left.



Scene from the spring Summit in Phoenix, AZ

Have a listen!

Now in its third season, BCAN Bladder Cancer Matters podcasts bring you enlightening, in-depth conversations with bladder cancer doctors, researchers, patients and caregivers. With more than 50 episodes, you can always find something that interests you. Scan the QR code below to choose the podcasts that interest you and here are some of our more popular episodes:

- What’s Up with Bladder Cancer and BCG with Dr. Ashish Kamat
- How Patients Can Navigate the BCG Shortage with Dr. Robert Svatek
- Quality of Life After Bladder Removal Surgery with Dr. Bernard Bochner
- Battling Aggressive Bladder Cancer in the Era of COVID - Margo’s Story
- I Can’t Get Chemotherapy to Treat My Bladder Cancer - Now What? with Dr. Guru Sonpavde



Scan to start listening



Leading the way to awareness and a cure

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www.BCAN.org/donate

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 and the families.

Make your recurring monthly donation today.

The Gift that Keeps on Giving – Monthly



www.BCAN.org/handbook

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

