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Tom Faced Bladder Cancer and Pancreatic Cancer at the Same Time

Tom is one of the more than 712,000 people living with bladder cancer in the United States. His story is a little different in that he had not just one, but two different types of cancer—at the same time.

Tom told BCAN that he had been suffering for years with what he now knows were bladder



Tom and his wife

cancer symptoms; frequent and painful urination. To try to discover what was wrong, Tom had multiple doctors' appointments and went so long without a confirmed diagnosis that he decided to change primary care physicians. His new doctor, after reviewing his medical records and hearing about his symptoms, insisted that Tom see a urologist to help find out more. Within three weeks, Tom saw a urologist who recommended a cystoscopy to get a better idea of what was happening. Once the results of the cystoscopy returned, the doctor confirmed that he had bladder cancer and suggested that his tumors be removed and biopsied. Prior to the cystoscopy, Tom's urologist ordered a CT scan to see if the bladder cancer metastasized to his kidneys.

Both bladder cancer and pancreatic cancer

As Tom received the results from the CT scan, the radiologist told him, "I have good news and bad news." He continued to say there was no cancer in either of his kidneys, but there was a large tumor on the body of his pancreas. Strangely, Tom felt a sense of relief because he finally knew what was causing his symptoms and was able to have a plan of action to save his life.

After receiving the news, Tom's urologist wanted to move fast. "My urologist was very proactive and made calls to get me into see a renowned pancreatic and hepatobiliary disease specialist." The two specialists worked together. First, Tom needed to have a TURBT, removal of the bladder tumor, and a

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...



Now that we are cautiously getting back to many activities we enjoyed pre-COVID-19 pandemic, we have been so happy to return to some of our in-person activities to better connect with members of our BCAN community. This past Spring brought the return of our in-person Walks to End Bladder Cancer. Walks took place in 14 cities throughout the U.S. and were also accompanied by a virtual walk for those who did not have a Walk near them. You will read more in the pages that follow, about the extremely successful Walk season surrounding May, Bladder Cancer Awareness Month. We would not have been able to accomplish so much without our group of dedicated volunteers.

Combining in-person and virtual events helps us reach so many more people. Recognizing that we learned during the pandemic that sometimes it may be easier for those in the bladder cancer community to attend events virtually, we held our second virtual Ask the Experts event on May 26. Our two bladder cancer experts, Dr. Sumeet Bhanvadia and Dr. Gopal Iyer, fielded dozens of questions from hundreds of viewers about the present and future of bladder cancer treatment.

This Fall, our in-person Summit for Patients and Families will take place on September 30 and October 1st just outside of Baltimore, MD. I can't wait to see members of our BCAN family face-to-face and share the joy of meeting in person once again.

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 and BCAN?
bcan.org/stories



Women



Young Adults



Caregivers



Men

modified Whipple procedure for his pancreatic cancer. He was elated to see how his care team collaborated so he could receive the procedures back-to-back to help reduce the time between surgeries.

Treating Tom's cancers

His urologist did the TURBT first, and the pancreatic surgeon did the modified Whipple procedure, removing Tom's pancreas body and tail, spleen, surrounding lymph nodes, and gall bladder. Tom stated, "I was in pretty good shape for a 71-year-old, and after a couple of days in the ICU and about a week in the hospital, I was home."

During the TURBT, the doctors removed what they had described to Tom as a T1 tumor that was very aggressive and scheduled him to come back in 90 days for another examination. After his follow-up visit and to his surprise, his cancer had progressed and was now muscle invasive. Having to go through yet another procedure was emotionally taxing on Tom, but he knew it was something he needed to do.

Next steps

Tom's urologist sat with him to discuss the next steps and treatment options for his bladder cancer. One was a radical cystectomy, having his bladder removed, and the other was bladder preservation. Tom wanted to keep his bladder. He underwent successful rounds of chemotherapy and radiation. It was not until a year and a half after finishing his treatments that the doctors discovered something new. Tom developed a carcinoma in situ (CIS) that the doctors suggested could have been from excessive radiation exposure. He accepted the latest difficult challenge and moved forward with another TURBT and BCG treatments.

Six years NED

Over the years, Tom faced many challenges with battling not one but two cancer diagnoses. Through it all, Tom has maintained his strength and faced his diseases head-on. Luckily for him, even though he has had two reoccurrences of bladder cancer and non-malignant growths, he has been six years with no evidence of disease for pancreatic cancer and

bladder cancer. Tom stated, "The quick and decisive actions of my primary care doctor, urologist, and pancreatic surgeon were the key to me beating the odds." Tom also says that his bladder cancer diagnosis oddly saved his life. If not for that diagnosis, he would have never known he had pancreatic cancer.




Tom R.

Though his journey was long, Tom maintained a positive attitude and trusted the support around him to help him get through the challenging times. Tom credits his wife of 50 years, Jan, for being a driving force in getting him through this. "If it wasn't for her, I do not know how well I would have gotten through these last five years of treatment," he told BCAN. Tom advises others battling cancer that having a strong support system is very important.

Finding BCAN

When Tom was first diagnosed, he was eager to find out more information about his bladder cancer. He was and still is thankful for the wealth of information on the BCAN web site that helped him learn so much more about bladder cancer and treatment options. Tom said, "I came across BCAN and it was a life changer for me."

Not only did he devour a great deal of information from the BCAN website, but he also felt compelled to join the BCAN community and give back by being a Survivor to Survivor (S2S) volunteer. The S2S program matches newly diagnosed patients with trained volunteers who have faced similar circumstances, offer advice and lend a sympathetic ear.

Tom credits his strength to endure partially to the people he met through the S2S program. He said, "I want to be a guide to help however I can and do offer them my perspective on what's it's like to battle bladder cancer." 

A Beacon of Hope for So Many

At BCAN, we are often told that one of the most important things that we provide is a sense of community that helps patients, caregivers and loved ones feel not so alone during their bladder cancer journeys.

There are so many courageous patients who battle this disease, dedicated caregivers who give selflessly, and hardworking medical and research professionals whose lifetime goal is to eradicate bladder cancer. For the second consecutive year as part of our Bladder Cancer Awareness Month celebrations, we asked our community to tell us about those who have served as that special beacon of light and hope in their bladder cancer journeys. Encouraging the BCAN community to nominate that special person: a caregiver, supporter or medical professional who have helped them cope with or eradicate this terrible disease, we received more than 80 nominations. From those, three finalists emerged. The BCAN community then voted on the person whom they believed was most deserving of the Beacon of Hope award. After nearly 600 votes, the 2022 Beacon of Hope Award was presented to long time BCAN volunteer, Karen Godfrey.

With BCAN nearly since the beginning


Karen is a bladder cancer survivor and is well known to many patients in the Inspire community. She has been involved with BCAN nearly since the organization was founded. She was nominated by two different people for the award. One said, "Karen holds a monthly bladder cancer support group. You can call her anytime. I was just very comfortable listening to her and her knowledge of bladder cancer seems to be unlimited." Another echoed how supportive and helpful Karen is, saying "Karen has spent numerous hours on the phone with me before and after my surgery. I texted her when I was in the emergency room at 7:00 am and she responded with a phone call. It was so reassuring to hear her calm and comforting voice as well as the course of action she suggested. I am so glad I was connected with this knowledgeable and helpful lady. She is the best!"

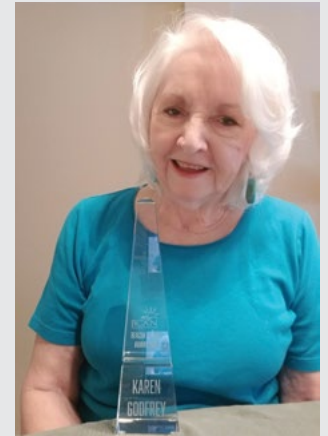
Other deserving nominees

The two other very deserving nominees were Dr. James McKiernan and patient advocate Bill Russell. Dr. McKiernan is a urologic oncologist at Columbia University Irving Medical Center in New York. One person nominating him said "Dr. McKiernan has been the most compassionate, understanding, articulate medical professional I have ever encountered."

Bill Russell, like Karen, is a bladder cancer survivor and patient advocate. Bill has been active with BCAN for many years, has participated in BCAN's Survivor to Survivor program and spearheaded the Pittsburgh Walk to End Bladder Cancer this year. One of the people who nominated Bill said "[He] was a great help to my brother, Rudy, giving him advice on how to deal with his ostomy and giving him encouragement when he needed it. He stayed in touch with Rudy just to talk and see if he needed anything until Rudy's passing."

Thank you!

We are very grateful to everyone who took the time to nominate that special person in their lives as well as to the nearly 600 people who cast their vote for a finalist. Next year's Beacon of Hope Award will open for nominations in April of 2023. 



Karen Godfrey with her Beacon of Hope Award



Scan this code to listen to Part 1 of Karen's Bladder Cancer Matters podcast interview with Rick Bangs.

Exercise your Free Will

Did you know that less than half of all Americans have a Will?

Having a Will done is one of those things that many know they have to do but put off. The process can appear unsettling, expensive or complicated. Nonetheless, preparing a Will can be a great way to support the people and causes you love.

As an affinity benefit for members of the BCAN community, we partner with FreeWill, an organization that provides an easy online solution for you to create your own Will – *FOR FREE*, often in less than 20 minutes.

Creating your own Will can be simple:


1. **Visit bcan.org/FreeWill** to begin the process.
2. **Follow the step-by-step instructions** to fill out the necessary information for your forms. You'll answer a few simple questions about yourself and your wishes.
3. **Print out the documents.** The information you provide is turned into precise legal language and presented back to you as a printable document.



This PDF document will include an instructions page, based on your state, and will guide you through signing and having witnesses sign the document to make your Will official.

4. **Sign the documents and keep them in a safe location.** As soon as you print out your Will and sign it in front of two witnesses, it is a valid legal document.

Doing a Will online is not an option for everyone, and FreeWill provides a searchable database of estate attorneys provided by the American Bar Association. FreeWill also gives your responses in an easy-to-read summary, which you can print and bring to your attorney to save time.

To get started, please visit bcan.org/FreeWill. If you have questions about adding BCAN to your own Will, please contact our Development staff at development@bcan.org or by phone at **301-215-9099, extension 202**. 

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

2022 Walk to End Bladder Cancer

BY THE NUMBERS

Total Number of Walkers: 2,555

Total Number of Teams: 230

TOP FUNDRAISERS

Dave Dimick

Ryan Ligon

Megan McLindon

Dan Miller

Kendra Froehlich

TOP FUNDRAISING TEAMS

UCSF Bladder Heroes

Brave for Dave

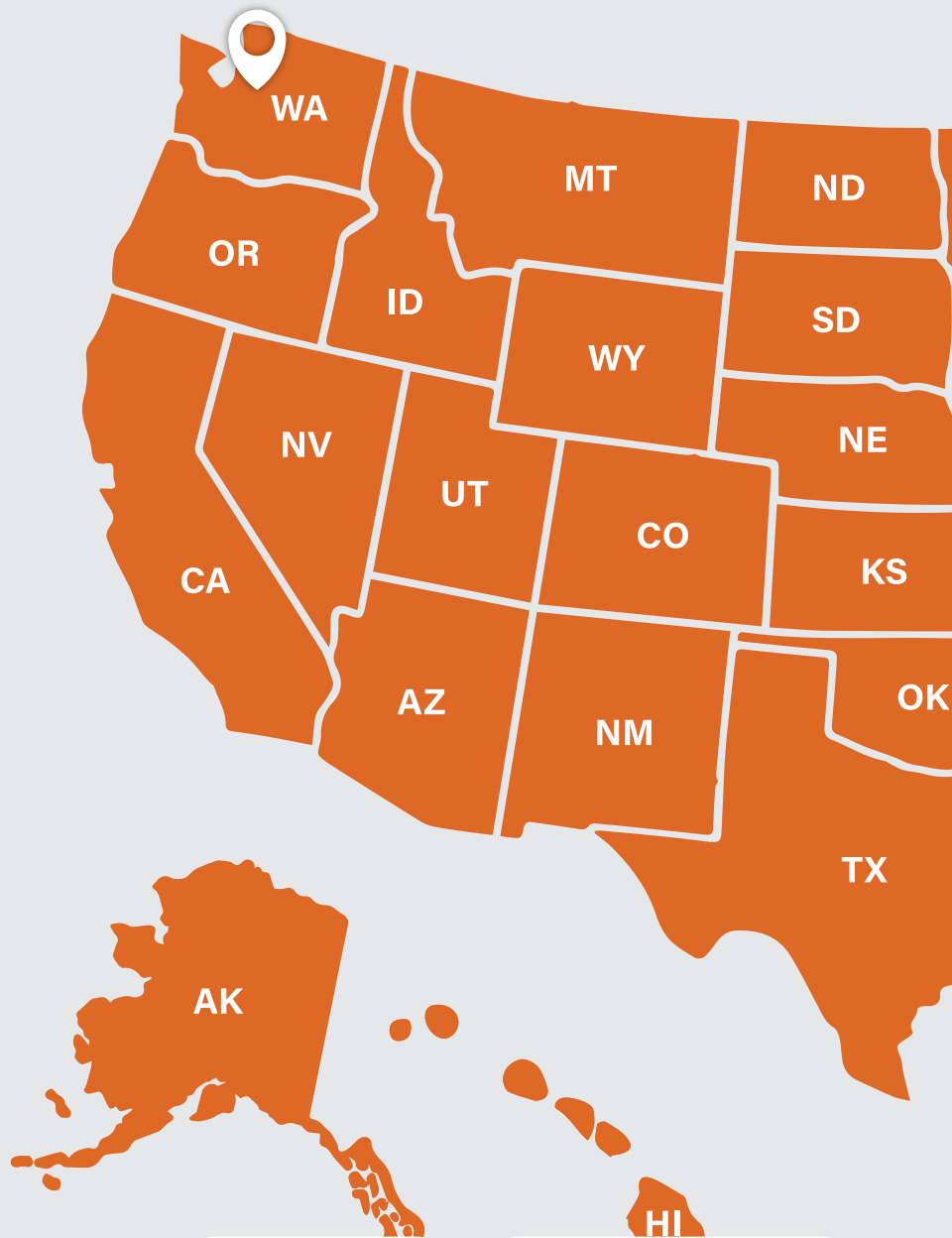
Team Froehlich

Doug's Dawgs

Rick's Highsteppers



VIRTUAL

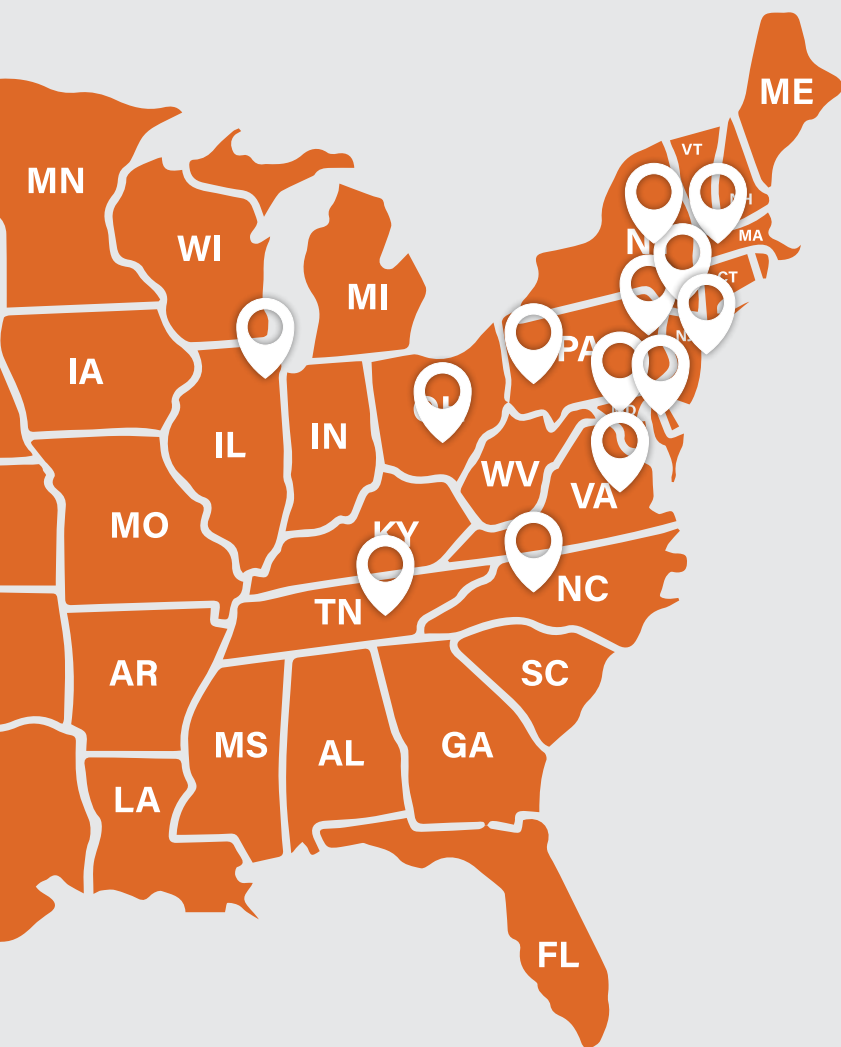


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Bladder Cancer Highlights



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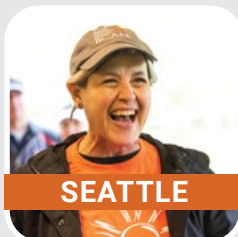
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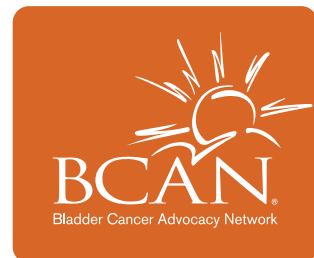
CHICAGO



PHILADELPHIA



SEATTLE



WALK TO END
BLADDER CANCER

NO ONE WALKS ALONE

BCAN Fuels the Careers of the Next Generation of Bladder Cancer Experts

In May 2022 during Bladder Cancer Awareness Month, BCAN announced the recipients of its four Young Investigator Awards. These awards support the development of exceptional early career research scientists and clinical cancer research investigators who are committed to improving the lives of bladder cancer patients. In 2022, there were four awardees from the many high quality entries received.

Each Young Investigator Award provides a \$50,000 grant that supports one year of early career bladder cancer research. The 2022 BCAN Young Investigator Awards were presented to:

- Raie Bekele, PhD, an Instructor of Radiation Oncology at Dana-Farber Cancer Institute in Boston
- Laura Bukavina, MD, MPH, a Urologic Oncology Fellow at Fox Chase Cancer Center in Philadelphia

- Weisi Liu, PhD, a Post-doctoral Fellow in Hematology and Medical Oncology at Weill Medical College of Cornell University in New York.

The 2022 Patient-Centered Clinical Research Young Investigator Award was presented to:

- Ava Saidian, MD, a Urologic Oncology Fellow from Moores Cancer Center at the University of California San Diego.

Andrea Maddox-Smith, BCAN's CEO, said of the awards, "Today's early-career bladder cancer investigators often become leaders in their respective fields. We are pleased to make investments in their careers to improve the lives of bladder cancer patients and those who love them," said Andrea Maddox-Smith, Chief Executive Officer of BCAN. "These awards would not be possible without the generosity of our donors. We are so grateful to them." 🙏



Raie Bekele, PhD.
Project: Dissecting the interplay between MAPK and PPARG signaling in bladder cancer



Laura Bukavina, MD, MPH. Project: Antitumor activity of Lactobacillus rhamnosus GG in murine model of bladder cancer



Weisi Liu, PhD. Project: Synthetic lethal strategies to limit tumor evolution driven by APOBEC3 activity in urothelial cancer.



Ava Saidian, MD. Project: Disparities in patient reported outcomes among Spanish speaking Latinx patients with bladder cancer

We're Back in Person and We Are Saving You a Seat!

We are excited to let you know that our annual **Bladder Cancer Summit for Patients and Families** will be held **in person** at the Westin Baltimore Washington Airport (BWI) Hotel on Friday, September 30 and Saturday, October 1. The Summit is a gathering in which bladder cancer patients, survivors and caregivers get together to share stories, support each other, become more effective advocates and also learn about present and upcoming medical advances in the field of bladder cancer.


During the Summit, attendees will also hear about recent and upcoming bladder cancer research in a panel featuring medical oncologist Dr. Jean Hoffman-Censits of Johns Hopkins Medicine and urologist Dr. Lambros Stamatakis of MedStar Health.

You'll also hear from Dr. Sermsak Lolak of Inova Health about addressing anxiety and fears that can accompany bladder cancer. The focus of the 2022 Summit is "Thriving and surviving."

By attending, you can learn more about nutrition, sexuality, and mindful meditations. You can also learn more about how BCAN's free programs and services can help you or your loved one in their bladder cancer journeys.



Just a few of the attendees at our last in-person Summit in 2019

The Summit is free to attend but registration is required. Save your spot by registering at bcan.org/summit22. 

Bladder Cancer Basics for the Newly Diagnosed

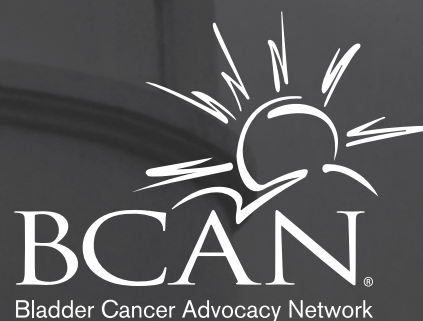
The newest edition of BCAN's handbook is now available, free of charge, to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. *Bladder Cancer Basics* contains more than 50 pages about bladder cancer signs, symptoms, diagnosis, treatment and survivorship.

Download your free copy today at bcan.org/handbook



Due to the kindness of people like you, for 17 years, the Bladder Cancer Advocacy Network (BCAN) has helped patients, caregivers, advocates, researchers and medical professionals strive for a world without bladder cancer.

Will you consider making a one-time or recurring donation to help us continue our critical work for bladder cancer patients and those who love them? Please use the enclosed envelope or make your donation online at **bcan.org/donate**.



A Successful Bladder Cancer Awareness Month

Bladder Cancer Awareness Month 2022 was 31 days dedicated to raising awareness about bladder cancer and sharing resources and information to help support patients, survivors and caregivers impacted by this all-too-common disease.

Each May, Bladder Cancer Awareness Month is a time for those in the bladder cancer community to join together and raise much-needed funds for bladder cancer research as well as patient education and support. It's also a time for patients, caregivers and loved ones to share their stories and honor those who have been impacted by this terrible disease. This year, our awareness month activities included:

Walks to End Bladder Cancer

Thanks to our amazing group of volunteers and walkers, we exceeded our fundraising goal and netted more than \$934,000 that will help BCAN continue to raise awareness of bladder cancer in the US, support those impacted by the disease, advocate for our community and advance bladder cancer research.

Beacon of Hope Contest

For several weeks in April and May, bladder cancer community members nominated their beacons – that special someone who has been a light in the darkness that bladder cancer can bring. Read more

A Podcast About Bladder Cancer

Did you know that there is a podcast by, for and about the bladder cancer community?

BCAN's "Bladder Cancer Matters" is hosted by patient advocate Rick Bangs. Episodes are conversations between Rick and medical professionals, patients and caregivers. Visit bcan.org/podcasts to listen.



about this year's Beacon of Hope Award winner, Karen Godfrey, on page 4.

We are deeply grateful to the bladder cancer community members who took the time to craft such compelling entries as well as to the more than 500 people who voted.




Dr. Gopa Iyer of Memorial Sloan Kettering Cancer Center



Dr. Sumeet Bhanvadia of USC Keck Medicine

Ask the Experts

May 25 featured our second virtual Ask the Experts program and more than 300 people registered for the event. Dr. Sumeet Bhanvadia of Keck School of Medicine of USC and Dr. Gopa Iyer of Memorial Sloan Kettering Cancer Center spent an hour answering bladder cancer patient questions, moderated by BCAN co-founder, Diane Zipursky Quale. 



Leading the way to awareness and a cure

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Free Bladder Cancer Webinars

BCAN is proud to offer patient insight webinars and treatment talks, bringing nationally recognized bladder cancer experts directly to patients and families to address important topics related to bladder cancer diagnosis, treatment, research and quality of life. BCAN brings leading bladder cancer experts in these free programs, directly to your phone, computer or tablet. Visit bcan.org/webinars to start watching now.

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 monthly donation will enable us to deliver multiple copies of our most popular publications to newly diagnosed patients and their families.

You can set-up your monthly donation today at bcan.org/donate.

