

Bladder Cancer Advocacy Network Newsletter

THE BEACON | SUMMER 2021 | BCAN.ORG



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Dan and Linda Miller along with Noel Lipman (center) at the 2021 Virtual Walk to End Bladder Cancer



A Beacon of Hope for Bladder Cancer

With an estimated 600,000 people living with bladder cancer in the United States, there are so many heroes. Courageous patients face frightening diagnoses, caregivers selflessly devote themselves to improving the lives of their loved ones, and medical and research professionals working so hard to end this terrible disease. BCAN wanted to give our community the opportunity to publicly recognize and honor those unsung heroes in the bladder cancer community.

During Bladder Cancer Awareness Month in May 2021, BCAN held our first-ever Beacon of Hope special recognition. We encouraged our community to nominate that special person who has been a shining light during their or someone else's bladder cancer journey. From the many nominations that we received, three finalists were chosen and then the BCAN community voted for the nominee whom they felt was most compelling. Ten-year bladder cancer survivor and supporter, Noel Lipman received the most votes, becoming the first-ever Beacon of Hope Award recipient.

Noel was nominated by Dan Miller, who is currently battling metastatic bladder cancer. Dan lives in the same community as Noel in South Carolina and he and his wife, Linda, became fast friends with Noel and her husband. Noel recently told BCAN, "I am honored that Dan felt that way about me to nominate me for the Beacon of Hope. I am so glad because I know that it means so much to him."

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THE BLADDER CANCER ADVOCACY NETWORK MISSION

To increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.

1-888-901-BCAN

WWW.BCAN.ORG

INFO@BCAN.ORG

A Note From Andrea...



For many of us, when the one-year anniversary of the COVID pandemic passed, we naturally looked back and gave thought to just how much things had changed in that short timeframe. For example, "Zoom" went from something kids do riding a bicycle or a skateboard to a daily, indispensable communications tool that we use to keep in regular contact with family, friends, and colleagues.

In light of our inability to meet in person, we have redoubled our efforts to bring our community the same high-quality programming and events as before, but in an all-virtual format. While it has been gratifying to be able to continue and enhance our patient and caregiver offerings online, I sure do miss seeing all of you in person. There is no substitute for the in-person hugs and warmth that we have shared in the past and I remain hopeful to return to in-person events in 2022.

It was a busy spring for the BCAN team. In the month of May, Bladder Cancer Awareness Month, we held our third Virtual Walk to End Bladder Cancer. More than 1,400 participants in 714 cities joined efforts to help support bladder cancer patients and those who love them. We are grateful to all of those who participated and donated.

At the end of May, we held our first-ever virtual Ask the Experts event in which two leading bladder cancer doctors answered questions from the more than 540 people who registered. The online format was very well received and we are grateful to have been able to address so many topics of interest for our community.

We will continue to offer virtual events and programming in the coming months like our annual Think Tank scientific meeting in August as well as our virtual Summit for Patients and Families on October 9, 2021.

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 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.

Dan was stunned when he received his diagnosis after a call from his urologist's office in which they gave him the news that no one wants to hear. They told him that he had bladder cancer and it was likely muscle-invasive. Dan was home alone at the time and when his wife, Linda, got home, he delivered the news to her and they were in a state of shock. That's when Linda contacted Noel, whom Dan told us "dropped everything and came right over."

Familiar with BCAN and the patient-focused information offered, Noel brought a copy of *Bladder Cancer Basics*, a handbook for newly diagnosed patients and walked Dan through it. She also shared quite a bit about her own journey with the disease. Dan told BCAN: "We talked. We cried. We shared. We learned a lot more about Noel's journey than what we ever knew."

Noel said, "BCAN was so helpful to me, and I knew the information could help Dan. That night, I was so happy to see the relief on his face after we walked through the information BCAN provided."

With a three-week wait for his next appointment with a urologic oncologist, Noel gave Dan the name of her urologist who connected him with Dr. Theodore

Gourdin of the Medical University of South Carolina (MUSC), whose specialty is urinary tract cancers. Dr. Gourdin saw Dan within a couple of days, thanks to the referral from Noel. That led Dan to participate in a clinical trial, something that he hopes to benefit from while helping to advance bladder cancer research for future patients.

Noel told BCAN, "Having been treated there, I knew that MUSC was an NCI-designated Comprehensive Cancer Center and Dan would get the best care possible."

Noel and her husband continually check in with and support Dan as he faces bladder cancer and a series of other complications, including a bowel diversion and colostomy. Dan admits to getting emotional when he talks about the support he has gotten from Noel. He told BCAN: "I was so happy that she won the Beacon of Hope Award. She just deserved it so much for the amazing support that she has given to Linda and me."

Noel added, "I don't really believe in destiny, but I think that Dan and I were just destined to meet and support each other." 🕯️

Michael's Cancer Journey

Bladder cancer is an insidious disease and has a high rate of recurrence. Michael Morigi of Staten Island, NY, has had bladder cancer *and* prostate cancer. Bladder cancer was his first bout with the "Big C."

In 2009, Michael was feeling off. He described it as a strange, "itchy" feeling in his stomach. He would continually scratch his stomach but the sensation would not go away. During a routine physical, his doctor told him that they had found blood in his urine, microscopic hematuria, which is not visible to the naked eye.

After some initial tests, the doctors told Michael that he was fine, but in about six months, the itchy feeling returned and he went to see a trusted nurse practitioner, Evelyn Goldstein. After some careful



Michael Morigi

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examination and a couple of tests, Evelyn told him “you have a problem with your bladder.” She recommended that he see a urologist and he went to see Dr. Louis Faiella, Director of Urologic Oncology in the Department of Urology at Winthrop University Hospital in New York.

In 2009, Michael was feeling off. He described it as a strange, “itchy” feeling in his stomach. He would continually scratch his stomach but the sensation would not go away.

Dr. Faiella ordered further tests for Michael. The exact day that he received his diagnosis (December 31, 2009) is forever etched in Michael's memory, as it is for many bladder cancer patients.

His doctor looked at him and said, “You have bladder cancer.” Michael told BCAN “...I really could not hear.... I saw his mouth moving, but all I kept thinking about was, ‘I have three kids. I have a wife and three jobs. Who's going to carry the ball?’”

Dr. Faiella asked him, “Do you understand what I am saying?” but Michael could only think of his family.

He told BCAN, “When someone says, ‘you have cancer,’ those are the worst words you hear in your life. I call it the ‘empty drum syndrome.’ My stomach felt hollow, like someone was banging on an empty drum.”

TURBT

Michael's bladder cancer was non-muscle invasive, so the next step in the process was a TURBT, a transurethral resection of a bladder tumor. Michael was concerned about the possibility of losing his bladder, but when he woke up from the procedure, the doctors let him know that his cancer had not grown into the muscle and that his bladder would be spared.

The doctors also told him that they did not think that they would be able to remove all the cancer and he needed to undergo BCG treatments. Soon after, he began six rounds of the BCG regimen.

Because of his prognosis and the fact that cancer had reappeared in his bladder only to be removed,



Michael with his grandchildren

again Michael was under close medical supervision. Between 2010 and 2016, Michael had routine cystoscopies every three months.

More bad news

In the summer of 2016, Michael was diagnosed with prostate and metastatic urothelial cancer of the renal pelvis.

Since prostate cancer progresses slowly, his doctors opted for watchful waiting and would monitor his condition carefully. As for the urothelial cancer of the renal pelvis, Michael told BCAN “I said, okay. This would be the third time they're telling me cancer, cancer, cancer. It's not that I wasn't scared, but I had been through this. I was handling it better.”

His doctors at Memorial Sloan Kettering told him that they would have to remove both of his kidneys and he would be facing a lifetime of dialysis. Eager to preserve one of his kidneys, Michael did research and pursued multiple second opinions and finally opted to change his medical team and be treated at Winthrop University, where they told him that they would work to spare his second kidney. Once again, he underwent surgery and the doctors at Winthrop removed one of his kidneys and its ureter, a nephroureterectomy. The cancer that appeared in Michael's remaining kidney was treated and he responded well to those treatments.

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Finding a clinical trial

Finally, given that Michael had metastatic urothelial cancer, his doctors advised that he seek future treatments at another facility that would be better equipped to handle his diagnoses – and perhaps even a clinical trial. His urologists recommended that he see Dr. Matt Galsky at Mt. Sinai Hospital in Manhattan.

Dr. Galsky is a Professor of Medicine and the Director of Genitourinary Medical Oncology, and Co-Director of the Center of Excellence for Bladder Cancer at The Tisch Cancer Institute at Mt. Sinai Hospital. Dr. Galsky has long been affiliated with BCAN and sits on its Scientific Advisory Board.

Michael lights up when he talks about Dr. Galsky. He recently told BCAN “He is the guy. Besides being my doctor, he’s become my friend. I have done many, many rounds of treatments and he’s been with me every step of the way. Dr. Galsky is an amazing man.”

Dr. Galsky happened to be running a clinical trial that he hoped would be effective at keeping Michael’s


cancers at bay. The trial that Michael enrolled in was the use of first-line single-agent immune checkpoint blockade for metastatic urothelial cancer, using Atezolizumab as part of a Phase III clinical trial. Dr. Galsky told BCAN, “...A subset of patients have remarkably durable responses to this treatment and often in the setting of few side effects. This has clearly been the case with Mr. Morigi, reinforcing the importance of first-line single agent immune checkpoint blockade as a treatment option.”

“All I kept thinking about was I have three kids. I have a wife and three jobs. Who’s going to carry the ball?”
— Michael Morigi, cancer survivor

Michael never really went through a “blame phase” but has thought about what might have caused his cancers. Before retiring because of his illnesses, he worked installing elevators in high rise buildings in New York for 30 years. Because of his experience, Michael worked extensively at the World Trade Center in New York, after both the bombing in 1993 and the destruction after September 11, 2001. In fact, he worked at the World Trade Center site for two years following 9/11.

At the time of this writing, Mr. Morigi is 100% NED – No Evidence of Disease. After so many rounds of treatment, it was only natural that he was wondering if he should continue in the clinical trial. He told BCAN: “I feel that the treatment is working for me. I’m not getting sick, I have no side effects and it would be terrible if I stopped and then something happened to me. So, I’m going to continue.”

With treatments every 26 days, full body scans every three months and a comprehensive blood work up every 28 days, Michael is used to spending time with his doctors. He joked that he feels like the “Six Million Dollar Man” because of all the care he receives. Having no evidence of disease has enabled Michael to do many of the things he loves, like cooking, caring for his grandchildren and exercising daily.

Despite everything he has gone through, Michael sums up his philosophy simply: “Every day I wake up is a privilege.” 



Cancer survivor, Michael Morigi

That's a Wrap!

A Successful Bladder Cancer Awareness Month

Each May, Bladder Cancer Awareness Month is a time for those in the bladder cancer community to join together to increase awareness of the disease and raise much-needed funds for bladder cancer research as well as patient education and support. We celebrated this year's Awareness Month with a host of activities, including:

Walk to End Bladder Cancer

Our community kicked off Bladder Cancer Awareness Month on May 1, 2021 with our Virtual Walk to End Bladder Cancer.

Thanks to all our wonderful supporters, we exceeded our fundraising goal this year and we will continue to expand our programs and services to help bladder cancer patients and those who love them. The graphic to the right shows just how much energy, enthusiasm and participation went into this year's Walk.

Beacon of Hope Contest

For several weeks in May, bladder cancer community members nominated their beacons – that special someone who has been a light in the darkness that bladder cancer can bring. Members of the bladder cancer community voted for one of the three finalists, the person whom they believed was most deserving.

We are deeply grateful to those bladder cancer community members who took the time to craft such compelling entries as well as to the more than 800 people who helped us select the first-ever winner, Noel Lipman.

Ask the Experts

May 26 featured our first-ever, virtual Ask the Experts event – more than 540 people registered for it. Dr. Kent Mouw of the Dana Farber Cancer Institute and Dr. Sarah Psutka of the University of Washington, two of the leading bladder cancer doctors in the United States, answered your questions for nearly an hour.

22 MILLION
STEPS TAKEN

11 WALK AMBASSADORS

1,443 PARTICIPANTS

169 TEAMS

714 CITIES

**46 STATES + DC &
PUERTO RICO**

11 COUNTRIES

**149 FACEBOOK
FUNDRAISERS**

11 NATIONAL SPONSORS

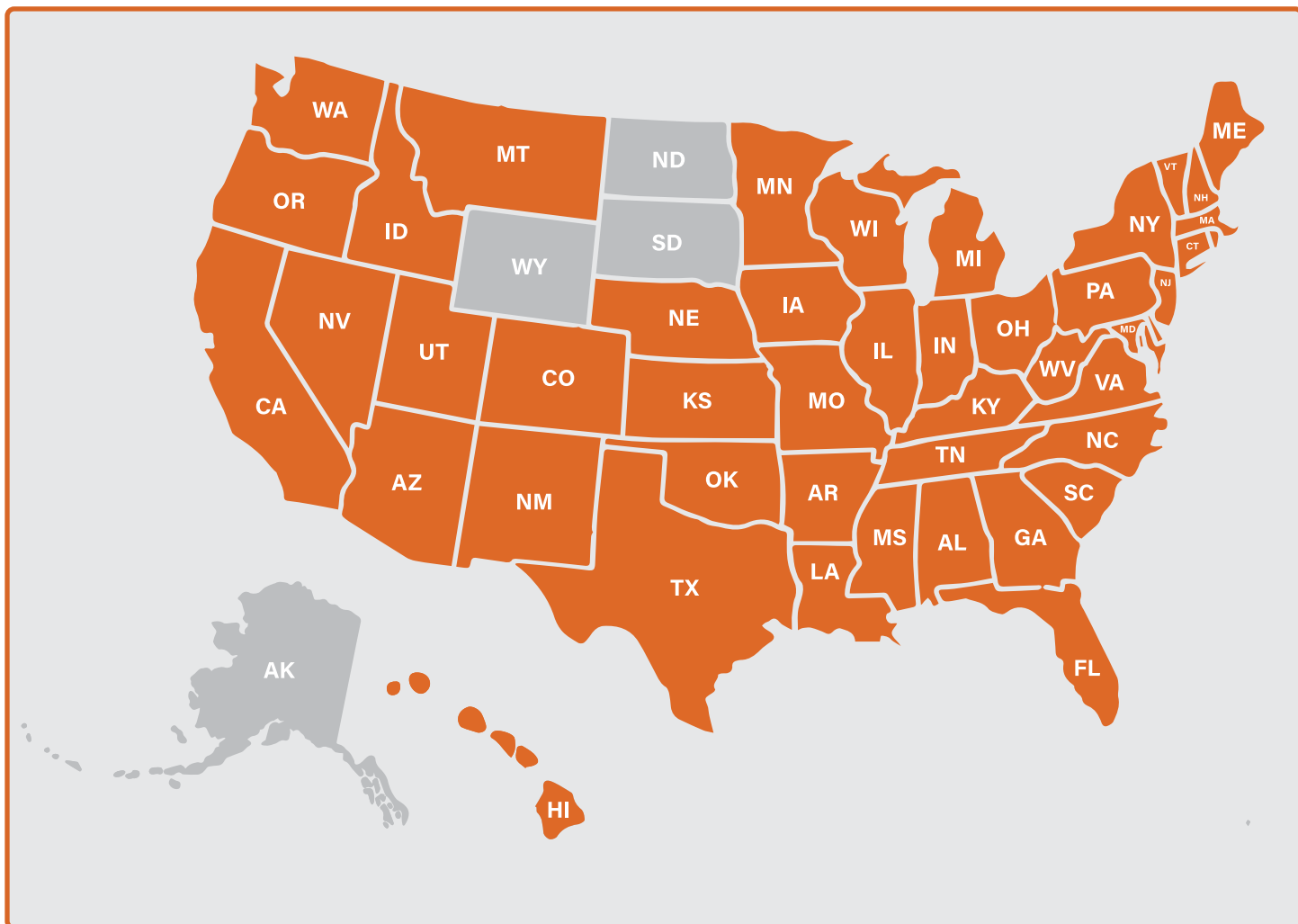
7 REGIONAL SPONSORS

**6 VOLUNTEER
COMMITTEE MEMBERS**

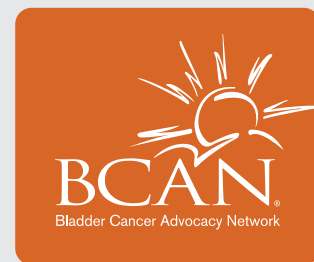
**MANY GENEROUS
DONORS**

**ALL ORGANIZED
AROUND 1 MISSION:**

**THANK YOU FOR HELPING TO MAKE THE 2021
VIRTUAL WALK TO END BLADDER CANCER A SUCCESS**



**INCREASE PUBLIC AWARENESS,
ADVANCE BLADDER CANCER RESEARCH,
AND PROVIDE EDUCATION AND
SUPPORT SERVICES FOR THE
BLADDER CANCER COMMUNITY.**



**VIRTUAL WALK
TO END BLADDER CANCER**

NO ONE WALKS ALONE



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

- Fund research for a brighter future
- Raise awareness that saves lives
- Enable BCAN to educate and support those who need it most

To make your gift to help others, please visit bcan.org/donate



Calling All Cheerleaders!

We are looking for volunteers to help make our 2022 Walks to End Bladder Cancer the best ever.

If you are interested, please send an email to walk@bcan.org to learn more about how you can help.

Supporting the Next Generation of Bladder Cancer Experts

In May 2021, BCAN announced the recipients of its five New Discoveries Research Young Investigator Awards. These awards support the development of outstanding early career research scientists and clinical cancer research investigators who have shown a commitment to improving the lives of bladder cancer patients. This is the first year that BCAN has presented five awards, noting the volume and quality of worthwhile entries received as well as the generous support of donors.

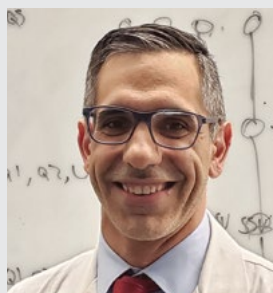
Each Young Investigator Award provides a \$50,000 grant that supports one year of early career bladder cancer research. The 2021 BCAN Young Investigator Awards were presented to:

- **Svetlana Avulova, MD**, Urologic Oncology Fellow at Mayo Clinic (2021 BCAN New Discoveries Young Investigator Award for Patient Centered Research)
- **Filipe De Carvalho, MD, PhD**, Urologic Oncology Fellow at Brigham and Women's Hospital in Boston (2021 Palm Beach New Discoveries Young Investigator Award)
- **Brendan Guercio, MD**, a Hematology/Oncology Fellow at Memorial Sloan Kettering Cancer Center in New York City (BCAN New Discoveries Young Investigator Award)
- **Benjamin Miron, MD**, Medical Oncology Fellow at Fox Chase Cancer Center in Philadelphia (2021 Palm Beach New Discoveries Young Investigator Award)
- **Eugene Pietzak, MD**, Assistant Attending Surgeon (Urologic Oncology) at Memorial Sloan Kettering Cancer Center in New York City (BCAN New Discoveries Young Investigator Award)

Andrea Maddox-Smith, BCAN's CEO, said of the awards, "It is our distinct pleasure to invest in such promising early-career investigators in their quest to develop innovative approaches to improve the lives of bladder cancer patients and those who love them. We also recognize the generosity of our donors who help make these awards possible. Thank you for helping us fuel today's research to provide tomorrow's improved outcomes. 📌



Dr. Svetlana Avulova



Dr. Filipe Carvalho



Dr. Brendan Guercio



Dr. Benjamin Miron



Dr. Eugene Pietzak

Same Great Information, New Web Site

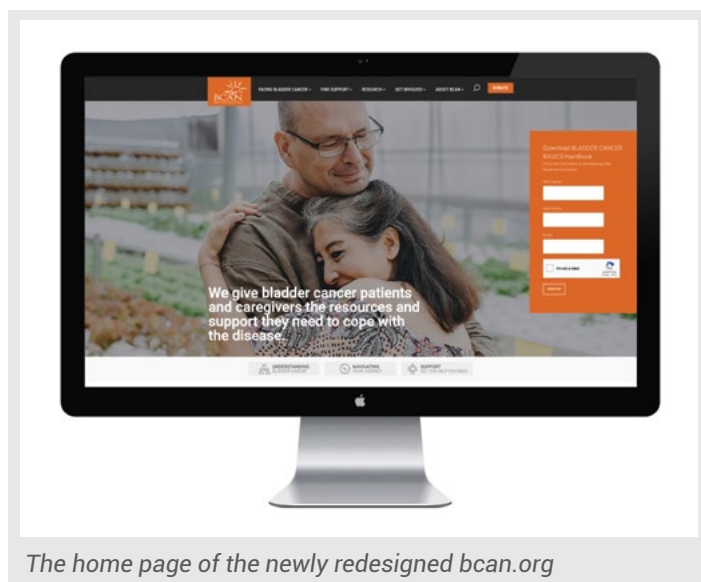
We have long recognized that our web site, bcan.org, is the front door both to our organization as well as the hundreds of pages of bladder cancer information and resources that we offer. With an eye on improving both the information on the site as well as the way it is presented, in May, we launched a completely redesigned site.

New site sections

When you visit our site, you will immediately notice a different look and feel and navigation. At the top, we have reorganized our content to make it easier to get the information you need. The "Facing Bladder Cancer" section contains links to bladder cancer explanations, patient stories as well as other free resources we provide to help navigate this disease. The "Find Support" is an A-Z compilation of available resources like online support groups, webinars, and other free offerings like our Bladder Cancer Matters podcast and our highly popular *Bladder Cancer Basics* handbook.

Highlighting bladder cancer research

No BCAN web site would be complete without a section on bladder cancer research, where you'll find



The home page of the newly redesigned bcan.org

information about our annual Think Tank scientific meeting, our Bladder Cancer Genomics Consortium as well as how BCAN funds ongoing research for both early-career and senior-level investigators who are working to find novel ways to defeat this disease.


We also have a newly designed clinical trials database that enables people to search for ongoing, recruiting clinical trials based upon their location as well as their type of bladder cancer.

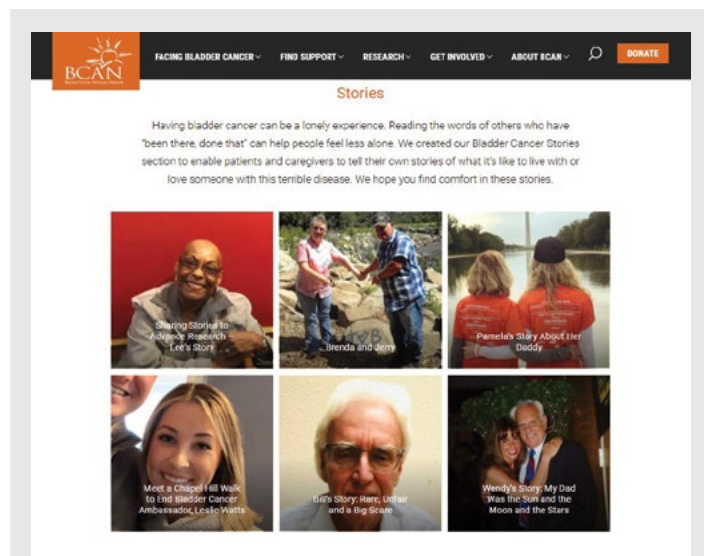
New clinical trials database

You'll also find new ways to get involved in our mission to end bladder cancer by volunteering, being an advocate, participating in our Survivor to Survivor program and making a donation to help us do even more.

Featured patient stories

Among the most popular sections on our web site are patient stories. In it, bladder cancer patients, caregivers and survivors share their journeys in solidarity with others who are facing a similar diagnosis or treatment. Patient stories are now featured both on the home page of our site as well as at the bottom of most other pages too.

Please visit our site today at bcan.org. 



Patient stories are prominently featured both on the home page of the site along with at the bottom of many other pages

2021 Virtual Summit

Once a year, the Bladder Cancer Advocacy Network brings together bladder cancer patients, survivors, and caregivers to share stories, experiences, and information about the disease at our Bladder Cancer Summit for Patients and Families. For the second consecutive year, we will be holding the Summit online and it will be easily accessible using a computer, phone or tablet.

This year's Summit will be held via Zoom on Saturday, October 9, from 12:00 PM-5:30 PM (ET). By being part of our meeting, you'll be able to:

- Hear leading bladder cancer experts discuss recent and upcoming bladder cancer research advances
- Connect with other patients and caregivers who truly understand your journey, and
- Learn more about how BCAN programs and services can help you



Smiling faces from the 2020 Virtual Summit for Patients and Families.

Registration is free and easy. Simply visit bcan.org/summit21 

Exercise your Free Will


As an affinity benefit for members of the BCAN community, we have partnered with FreeWill, an organization that provides an easy online solution for you to create your own Will – FOR FREE.

Creating your own Will can take less than 20 minutes. Simply:

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 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.

Online estate planning isn't suitable for everyone so if you have more complex needs, 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 Anita Parker, Director of Development, by email at aparker@bcan.org or by phone at 301-215-9099, extension 202. 





Leading the way to awareness and a cure

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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 patients want to know more about things like what to expect with a surgery or procedure, what to expect with treatment, and how other survivors approached getting back to "normal."

If you are a bladder cancer patient and would like to be matched with a survivor, please call **301-215-9099** and leave a message at extension 212. You can also send a confidential email to mustout@bcan.org.

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.

