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Dancing Her Way through Bladder Cancer – Anne Doesn't Miss a Beat

New Hampshire native, Anne Theriault now lives in Maryland. Anne spent many years in non-traditional careers with the Bureau of Prisons and the US Army. She deployed to combat zones four times in her military career and began taking up ballroom dancing after a challenging combat tour in Iraq. "I just did it socially, and not competitively. When I found the Arthur Murray Dance Studio, I decided to go ahead and dance competitively." Dancing was part of her plan for retirement. Unfortunately, in 2017 she was diagnosed with a rare form of bladder cancer.

"When I noticed blood in my urine, my clinic gave me prescriptions for three rounds of antibiotics. I finally made it to a urologist and had a cystoscopy. The

following day I completed a CT scan and blood work. A week later I was in surgery



for about three hours to have the tumor removed." When the results came back, Anne was told that she had a sarcomatoid carcinoma, a rare form of bladder cancer that is considered the most untreatable and the most aggressive.

"I am fortunate to be here in the Baltimore area. Someone recommended I have a second opinion, if not a third." Anne went to Johns Hopkins Medicine where she met Drs. Trinity Bivalacqua and Noah

Continues on Page 4

OUR MISSION

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

A note from Andrea...



The Bladder Cancer Advocacy Network (BCAN) is starting off 2018 with momentum, commitment and hope in our work. Today, over 600,000 Americans are living with bladder cancer and according to the National Cancer Institute, bladder cancer is the 6th most common cancer in the United States, yet most people are unaware of the disease, its risk factors and treatments.

Understanding that we are still living in a time of unimaginable ignorance about bladder cancer, we have launched an awareness campaign that propels our message to the vast majority of Americans who do not realize they can get cancer in the bladder. BCAN believes greater public awareness will lead to better treatments and ultimately a cure.

This comprehensive campaign* includes a video that will play in doctor's offices across the country, disseminating a newly created bladder cancer awareness quiz (see page 7), a robust Facebook campaign, a radio tour and a new advertising relationship with AARP. Stay tuned as we roll out this campaign in an effort to put bladder cancer at the forefront.

In this issue of **The Beacon** you will meet Anne Theriault, a bladder cancer survivor, who uses dancing to keep motivated and thereby motivating everyone around her including her healthcare team. You will meet Noah Hahn, Anne's doctor and a member of the BCAN Scientific Advisory Board. Dr. Hahn shares his observations and suggestions on how patients can be active participants in their care.

Finally, we feature information on BCAN's focus and commitment to research and, as a reader, you will get a glimpse into how we do it. And, believe it or not, it's time to pull out the gym shoes and sign up to Walk to End Bladder Cancer at one of our 25 plus sites around the country. Also coming this month is the BCAN store, so feel free to order your BCAN swag for Bladder Cancer Awareness Month in May.

So much is possible when we come together with amazing supporters like you. On behalf of everyone impacted by bladder cancer, **THANK YOU!**

With grateful appreciation,

A handwritten signature in black ink, appearing to read 'Andrea'.

Andrea Maddox-Smith
BCAN Chief Executive Officer

*The 2018 Bladder Cancer Awareness Campaign is made possible by a generous contribution from The Family of George Ruffo.

A promotional graphic for the BCAN store. It features the BCAN logo (a sunburst icon above the text 'BCAN' and 'Bladder Cancer Advocacy Network') on an orange background. Below the logo is a grey banner with the text 'BCAN STORE NOW OPEN!'. Underneath are two images: a grey polo shirt and an orange zip-up jacket, both with the BCAN logo. At the bottom is a grey banner with the URL 'https://stores.inksoft.com/bcan'. The entire graphic is decorated with several overlapping squares in shades of orange and grey.

BCAN
Bladder Cancer Advocacy Network

BCAN STORE NOW OPEN!

<https://stores.inksoft.com/bcan>

BCAN Focus on Research



Since 2005, BCAN's mission has focused on three main areas. The first is to increase public awareness of bladder cancer. We also provide education and support to those with bladder cancer. But the one area that has the greatest potential to change the landscape of bladder cancer is our effort to advance bladder cancer research.

To date, our donors have enabled BCAN to contribute \$2,300,000 to support bladder cancer research for twelve early career Young Investigator Awards (YIA) and four Bladder Cancer Research Innovations Awards. Also, the John Quale Travel Fellowship has supported 36 post-doctoral fellows with bladder cancer research interest to attend the Bladder Cancer Think Tank since 2009.

BCAN has funded \$2.3 million in research at 26 prestigious medical/academic institutions across the US so far...

Our Bladder Cancer Research Network volunteer experts apply a rigorous evaluation process to help us select the most promising science to support. Each application is reviewed and scored by a Scientific Review Group comprised of medical experts respected for their accomplishments in cancer research, and as leaders in the field. We are eager to see which proposals focusing on the microbiome, or microenvironmental determinants of bladder cancer metastasis will be funded with our Innovation Award this year. We have added a new YIA this year to support transformational patient-oriented clinical bladder cancer research (e.g., studies of access to care, quality of care, quality of life, health disparities, and patient-centered outcomes research).

Of course, none of this important work would be possible without the generous support of donors like you. If you have contributed to our bladder cancer research efforts, on behalf of patients and survivors, thank you for helping to change the landscape and advancing bladder cancer research.



Interested in contributing to bladder cancer research?

Visit www.bcan.org/donate

Hahn. They recommended chemotherapy followed by a cystectomy due to the size and aggressiveness of her tumor. "I didn't have that much time to think," Anne explains.

"At age 57, I was not a typical bladder cancer patient. I was not male, and I am not a smoker. I didn't have any known risk factors for bladder cancer. I had no idea what I was getting into because I had never heard of bladder cancer before."

BCAN and people I spoke with from the hospital were a big help. I had every intention of having a neobladder, but could not because of the type and location of my cancer," noted Anne. So, instead she received an ileal conduit after her cystectomy.

"The medical staff at Johns Hopkins calls me a motivated patient because I tend to continue to do everything I want to do, without slowing down too much. Having the right people in your life and the right medical staff to make things happen for you is important," Anne laughed. When asked if having an ileal conduit slowed her down, she replied "It is amusing because everybody tries to baby you. But bladder cancer doesn't stop me. Even after I've had a long round of chemotherapy, I think 'I have to go dancing tonight.' Dancing has been my outlet, my true network of people, and my real happy place when I was sick. I could've been very depressed with some of the news that I kept getting. But two weeks after my chemotherapy ended, I was competing on the dance floor."

"Within six months of having the cystectomy, I competed in the most prestigious ballroom dance competition in the world."



Anne with her dance instructor, Joe Howard, *Nine Dance National Champion* | Arthur Murray, Columbia, MD

Blackpool, (a ballroom competition with a 93-year history in England) finally admitted Pro-Am dancers in 2017 and Anne's dance teacher brought her to England to compete. She recalls, "he kept reminding me that it doesn't matter where you place. Just think of where you were last year at this time and how challenging your life was."

Anne continues "I know a lot of people have been hesitant about taking trips or going on real adventures after having a cystectomy or having major surgery or chemo, but for me dancing motivated me to keep going."

"I just had my first year CT scan, and it was clear of cancer." Anne recalls her doctor, Noah Hahn commenting,

"In all the scenarios that we tried to evaluate and guess, we never would've predicted your outcome, based on the diagnosis you had."

She credits dancing for helping her get through that stressful year with a positive outcome. "Right now I want to give back so I go to several meetings at Johns Hopkins, and I attended my first BCAN Leadership Summit in 2017. I'm trying to navigate how I'm going to fit in and give back to people."



Leadership Summit 2017

Anne is now out of the military (having a cystectomy no longer allows her to deploy overseas) and she intends to investigate a possible connection of her bladder cancer to her military service. "I was lucky I didn't have to fight



Anne serving in Afghanistan

for health care through the military because I had federal government insurance benefits." Her medical staff believes that exposure to uranium, petroleum and many chemicals in combat zones where she deployed may have been a risk factor for Anne developing bladder cancer.

Though she feels like a rookie in the bladder cancer world, Anne has information that people can use. "It is very humbling to me that people come up and say, 'You're the first person I met that has bladder cancer and has an ileal conduit,'" notes Anne. "I didn't realize how sick I was before all the surgeries and procedures that I had done. Now physically, I almost feel stronger, with the help of my physical therapist, of course. Her mission was to make sure that I have great movement so that I can continue to dance, because that is my priority."

"My dance community means very much to me, but so does the staff and all the workers at Johns Hopkins and BCAN. The more I learn, the more I realize that this was a very dangerous situation," reflects Anne. "After the cystectomy, I didn't dance for a month. I feel very lucky." While bladder cancer was a big part of her life for a year, it is not defining Anne now!

If you want encouragement, visit www.bcan.org/dancing-through-bladder-cancer to see more photos and watch videos of Anne and her instructor dancing!



My Bladder Cancer Story

Read more than 30 stories of patients and caregivers. What is your bladder cancer story?

www.bcan.org/my-bladder-cancer-stories



Young Adults



Men

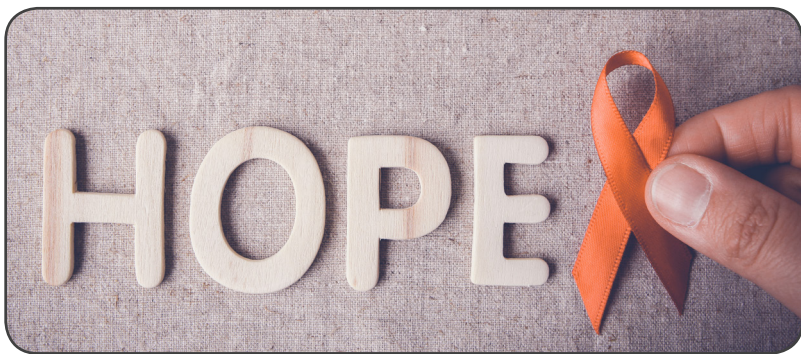


Women



Caregivers

May is Bladder Cancer Awareness Month!



“Never underestimate the impact your personal experience and passion can have on improving and maybe even saving the lives of others.”

- Diane Z. Quale, BCAN Co-Founder

We commemorate Bladder Cancer Awareness Month with public service announcements, increased education, and a greater emphasis on strengthening the bladder cancer community. Through a new relationship with AARP, we hope to reach 24 million people. Raising public awareness is the first step towards finding a cure.

We need your help! Join BCAN this May and all year long to bring bladder cancer awareness to the forefront. Share your story. Talk about your symptoms and your cancer journey. Join one of our Walk to End Bladder Cancer events (see page 8). You will not only increase awareness of the disease, but you could help save a life.

In 2018...

more than

81,000

will be diagnosed

over

17,000

will die



4th

most
common
cancer



11th

most
common
cancer

WHAT WILL **YOU** DO THIS MAY?

EMAIL US AT **INFO@BCAN.ORG** TO SHARE YOUR AWARENESS MONTH ACTIVITIES!



Get ready for Bladder Cancer Awareness Month with BCAN gear from the BCAN Store (see page 15).

Take part in our social media campaign and spread the message.



TAKE ACTION

Copy and cut out the “Bladder Cancer Awareness Quiz” on the next page. Share with family, friends, co-workers and other members of your community!



Marge Coffin, PA Chapter President, petitioned to have the Pennsylvania State Capital lit orange in May 2017

BLADDER CANCER AWARENESS QUIZ

Answer the following questions to learn how much you know about the risks and warning signs of bladder cancer.



1. How old are most bladder cancer patients when they are diagnosed?

- ☐ Less than 40 years
- ☐ 40-59 years
- ☐ 60-69 years
- ☐ 70 years or older

2. Which gender has higher rates of bladder cancer?

- ☐ Men
- ☐ Women

3. Which of the following are known to increase the risk of developing bladder cancer?

- ☐ A history of smoking
- ☐ Exposure to chemicals at work or in your environment
- ☐ Treatment for other cancer
- ☐ Chronic bladder or urinary infections

4. Which group has higher rates of bladder cancer?

- ☐ Caucasian
- ☐ African-American
- ☐ Hispanic
- ☐ Asian

5. Which of the following might be a sign of bladder cancer?

- ☐ Blood in your urine
- ☐ Irritation when urinating
- ☐ Change in the urge or how often you need to urinate

To learn more about bladder cancer, visit the **Bladder Cancer Advocacy Network** at BCAN.org or call 888-901-BCAN.

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ANSWERS

1. Bladder cancer can occur at any age but your risk increases as you age. The average age at diagnosis is 73.
2. Men are four times more likely to develop bladder cancer than women. Yet women are often diagnosed at a later stage of bladder cancer.
3. All of these are known to increase the risk of developing bladder cancer. Learn more at www.bcan.org/
4. **signs-risk-factors.** Caucasians are twice as likely to develop bladder cancer as are African-Americans or Hispanics; Asians have the lowest rate of bladder cancer. African Americans are more likely to have more advanced disease when diagnosed and are twice as likely to die from the disease.
5. All of these may be signs of bladder cancer. But they may also be signs of other urinary tract diseases. Be sure to see a urologist, the doctor who specializes in diseases of the urinary organs.

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2018 BCAN Walk to

Spring 2018: April, May, June

Since 2011, these volunteer-driven events have given voice to patients, survivors, caregivers, friends, family, and those who have lost loved ones to bladder cancer.

BCAN Walk to End Bladder Cancer has raised more than **\$3 million** toward bladder cancer education, awareness and research.



www.bcanwalk.org

Walk with us at these locations:

Albany, NY
Baltimore, MD
Boston, MA
Central Ohio
Central Pennsylvania
Chapel Hill, NC
Chicago, IL
Corpus Christi, TX
Dallas/Fort Worth, TX

Detroit, MI
Fort Walton Beach, FL
Houston, TX
Huntsville, AL
Jersey Shore, NJ
Las Vegas, NV
Lehigh Valley, PA
New York City, NY

Omaha, NE
Philadelphia, PA
Pittsburgh, PA
Richmond, VA
San Diego, CA
San Francisco, CA
Seattle, WA
Suffolk County, NY
Washington, D.C.

End Bladder Cancer

BCAN's Signature Awareness Event – 8th Season



We invite you, your family
and your friends to join us as
we walk and make a difference
– **one step at a time.**

REGISTER TODAY

www.bcanwalk.org

**and help lead the way to
awareness and a cure.**

**Cost: \$25 Adult
\$5 Child (under 18 years)**

**Thank you to our generous
National Sponsors!**

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SERONO**

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FOUNDATION

PHOTOCURE
®

Waltzing with Anne Through Her Bladder Cancer Journey



“Anne is an incredible example of a patient who refused to be paralyzed by her diagnosis of cancer. She had an incredibly positive attitude from the beginning. She is a very active and motivated person. That didn’t change just because she was diagnosed with cancer,” noted Dr. Noah Hahn, Deputy Director of the Greenberg Bladder Cancer Institute at John’s Hopkins Medical. He spoke with BCAN about Anne’s more aggressive variant of bladder cancer known as carcinosarcoma or sarcomatoid bladder cancer. This uncommon type of tumor tends to be more aggressive, and the outcomes tend to be worse than patients with the same stage of bladder cancer that do not have sarcomatoid features in their tumor(s). Dr. Hahn estimates that it probably accounts for 5% to 10% of all bladder cancers.

Dr. Hahn recalls Anne saying, “If we’re going to do chemotherapy now, and surgery six to eight weeks or so after that, I’ve got plans next year to participate in some important dance events, so you need to work with me to get me in shape for that.” He continues, “Anne is a good example of a patient being able to work with her medical team to devise a schedule, for initial treatment, the surgery, and rehab, with some very specific life goals in mind. Physicians are sometimes very focused on the disease-specific timelines and goals.”

“We really do care about the whole quality of life and other things that are going on with patients, but it helps when a patient is an interactive part of that treatment planning process.”

From the very beginning, Anne set some goals for herself, and for her health care team. “I would emphasize that in this process Anne never overstepped any boundaries. It was never a pushy type of relationship. From the beginning, she said, ‘This is where I want to be a year from my surgery, and I want your help to get me there. How do we do this?’” Dr. Hahn explained “We are fortunate at Hopkins. Like many medical centers that perform a lot of cystectomies, we have great resources. These include the nursing team in post-op and, even on the urology floor. We have ostomy nurses available in the first months to get patients informed on how to manage their diversions.”

Another thing that Dr. Hahn felt was instrumental is that Anne brought members of her family and her support system to each of her visits. It was very clear from the beginning that if Anne needed some help, or if she was having a down day, there were people there that she could lean on when she needed them most. “Anne’s overall attitude and the way she carries herself in everything that she does put her in a position to have the best result. So I think that can be a real example to others,” he said. He went on to share some observations and suggestions other patients can use to be active participants in their care.

- Don’t be afraid to be in the game. It is your healthcare. That is what Anne did from the very beginning.
- Anne would be the first to admit that she doesn’t have all the answers. There are days when she’s down but she’s not afraid to jump in and be a part of the process.
- I think every patient may have something in their life that they can draw strength from like Anne did with dancing. We need patients not to be afraid to come off of the sidelines and be a part of their care. She is a good example of how beneficial that can be.
- Patients should be proactive and just ask their physician, “We have talked about what we’re going to do for my treatment plan, and I do have a few concerns I’d like to talk about with you. They have to do with some of the goals of my life and the direction we are heading with my healthcare. Would it be okay to talk about that?” I think that can be very productive. But I would encourage patients to feel comfortable bringing it up.

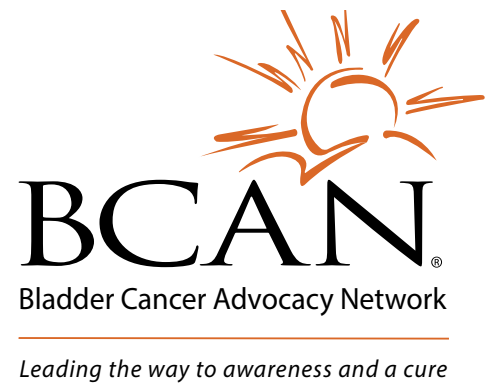
“Anne is incredible, and every time she comes back to the clinic, it is a big pick me up when I see her name on the schedule because I’m thinking, all right, this is going to be good.”



**Buy low.
Give high.**

More simple ways to make your mark on the future:

- Make a gift through your will or estate
- Make a gift through your retirement plan
- Give life insurance you no longer need
- Consider a gift of real estate
- Make a gift that gives fixed payments for life
- Make a gift that protects your assets



A strategic way to give. It's a 100% win-win.

You can make a big difference for the Bladder Cancer Advocacy Network and gain a double tax benefit for yourself. How? It's easy. Donate appreciated assets like stocks, bonds or mutual fund shares.

- Claim a charitable tax deduction on the full fair market value.
- Pay no capital gains tax on the appreciation.
- In some cases, your gift "costs" less than the tax deduction you gain!

So you end up with more money in your pocket, and more of your assets' value goes to support bladder cancer awareness, patient education, and research.

Interested?

Contact us or visit our website to learn more about this and other easy, effective giving strategies that don't affect your cash flow and endure for generations to come.

Anita Parker

Director of Development
Bladder Cancer Advocacy Network
4915 St. Elmo Avenue, Suite 202
Bethesda, MD 20814



aparker@bcan.org

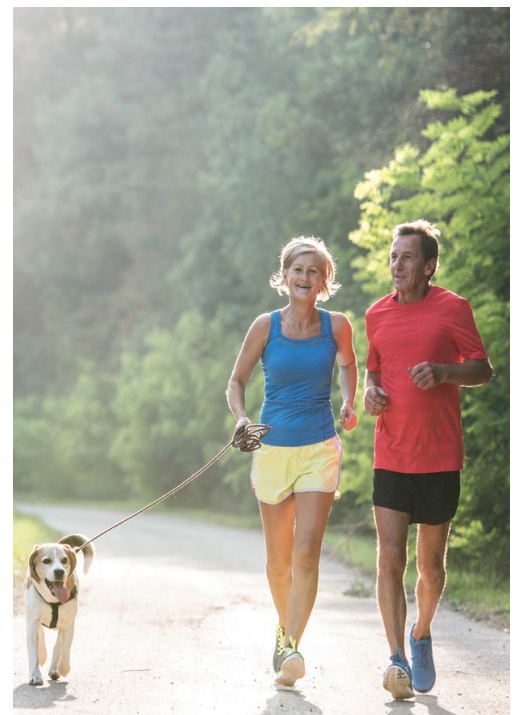


bcan.plannedgiving.org



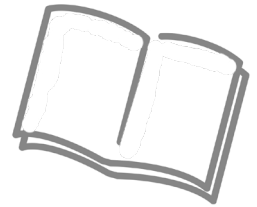
301-215-9099 ext. 202

Help us continue the work we do on behalf of the bladder cancer community – for generations to come.



Educational Resources

Learn about your disease.
Be active in your care.

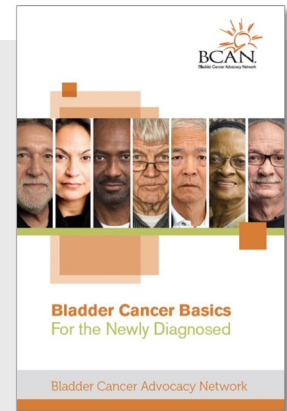


Bladder Cancer Basics for the Newly Diagnosed

BCAN's recently updated and redesigned handbook is available, free of charge to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options to enable them, with the help of their medical team, to make informed choices about their continued medical care.

Available for download or have a free hard copy mailed.

www.bcan.org/handbook



Bladder Cancer Clinical Trials Dashboard

Visit our dashboard to learn about the most up-to-date information on bladder cancer clinical trials and search by disease type and in multiple states.



clinicaltrials.bcan.org

Patient Insight Webinars

Nationally recognized bladder cancer experts address important topics related to bladder cancer diagnosis, treatment, quality of life, and ongoing research.



www.bcan.org/webinars

“Get the Facts” Single Topic Sheets

Nationally recognized bladder cancer experts address important topics related to bladder cancer diagnosis, treatment, quality of life, and ongoing research.



www.bcan.org/get-the-facts

Expert Explanations

Leading experts provide in-depth information on bladder cancer topics:

- Bladder Cancer Preservation
- BCG



www.bcan.org/expert-explanations

The New Normal | Living with a Urinary Diversion

Bladder cancer survivors give voice to their choice, illustrating the day-to-day impact these surgeries have on a survivor.



www.bcan.org/the-new-normal

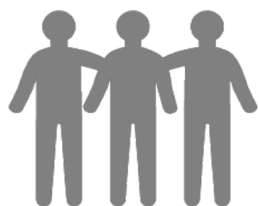
Conversations: Let's Talk About Bladder Cancer

BCAN Co-Founder Diane Zipursky Quale interviews experts who speak on research, treatment and quality of life.



www.bcan.org/lets-talk-about-bladder-cancer

Cancer Patients and Caregivers



Support Services

You don't have to do this alone.
BCAN is here to help.

Survivor 2 Survivor

Survivor 2 Survivor connects diagnosed patients and caregivers with other survivors or caregivers who have gone through their own bladder cancer journey.



Call 888-901-2226 (BCAN) ext. 212

BCAN Connection

A support line staffed by volunteers for anyone affected by bladder cancer. Volunteers provide practical information and resources to assist bladder cancer patients and their loved ones.



Call 888-901-2226 (BCAN) ext. 207

In-Person Support Groups

Bladder Cancer Support Groups are listed on this webpage by state.

Canadian groups are at the end of the list.

www.bcan.org/in-person-support-group

BCAN on Inspire

BCAN's online support community for bladder cancer patients, survivors and caregivers with nearly 30,000 members.

www.bcan.org/online-support-community

Veterans and Bladder Cancer

See resources for veterans, including a Patient Insight Webinar focused on the physical and emotional impact of bladder cancer unique to our veteran population.

www.bcan.org/veterans-bladder-cancer

Women and Bladder Cancer

Many women dismiss blood in their urine and are often misdiagnosed resulting in a delayed and more advanced diagnosis. Learn more about resources for women.

www.bcan.org/women-bladder-cancer

Do you want to lend an ear and offer support to others?

Being diagnosed with bladder cancer can leave someone in a scary and lonely place, feeling uncertain of what you may be facing. Talking to a BCAN volunteer may help.

Survivor 2 Survivor

Through virtual connections, volunteers provide firsthand accounts of life with a bladder cancer diagnosis.

BCAN Connection

Volunteers fully staff this information and referral line, assisting patients and caregivers with questions they may have.



“Most people are afraid of the unknown and just want their fears alleviated.”

- Survivor 2 Survivor Volunteer

Interested in volunteering?



Email **volunteer@bcan.org** for more information.

New volunteer trainings coming soon!

BCAN Chapters | Find Support in Your Community

A BCAN Chapter is a group of volunteers who share BCAN's vision in changing the lives of those affected by bladder cancer; a group of people just like YOU that have been touched by bladder cancer themselves in some way.

Finding support through your regional chapter is a wonderful way to not only have important questions answered, but to make lifelong friendships with people who know exactly what the bladder cancer journey can be like.

Visit
www.bcan.org/chapters
to learn more.

Locations

Contact

Albany, NY	Albany@bcan.org
Corpus Christi, TX	CorpusChristi@bcan.org
New Jersey (all)	NewJersey@bcan.org
Las Vegas, NV	LasVegas@bcan.org
Pennsylvania (all)	PAchapter@bcan.org
San Diego, CA	SanDiego@bcan.org
Greater Omaha, NE	Omaha@bcan.org
Dallas-Fort Worth, TX ...	dfwchapter@bcan.org
Triangle, NC	nctchapter@bcan.org

Join us @ the 2018 BCAN Leadership Summit in Houston, TX

October 12th-13th, 2018



To connect...

Meet your buddies from the Inspire community. Share BCAN volunteer strategies. Make new friends who really do understand what it means to live with bladder cancer!



To reach & teach others...

Get tips, tools and tactics to teach and raise awareness about bladder cancer in your community!



To learn about advances in research...

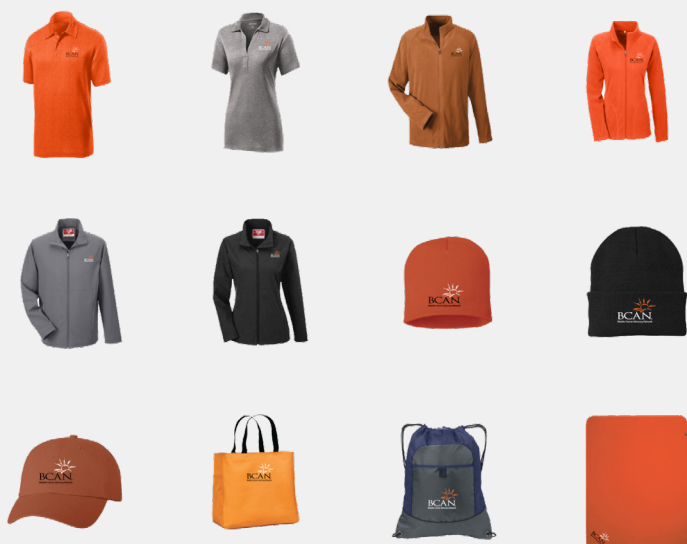
Listen as top bladder cancer researchers share new developments and exciting bladder cancer research on the horizon.

“I feel exhilarated. Meeting and talking with other bladder cancer patients and sharing our stories provided amazing support to us all.”

- Leadership Summit 2017 Attendee

Register now and learn more at www.bcan.org/2018-Leadership-Summit

BCAN STORE NOW OPEN- SHOP TODAY!



**Support BCAN.
Order your gear for
Bladder Cancer
Awareness Month!**

<https://stores.inksoft.com/bcan>



Leading the way to awareness and a cure

4915 St. Elmo Avenue, Suite 202
Bethesda, MD 20814

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Join us to learn about the role and impact of clinical trials in the advancement of bladder cancer treatment and new drug development. Find out what's on the bladder cancer research horizon. Get tips on the best practices to raise awareness of bladder cancer in your community. Hear about how you can make your voice heard in key bladder cancer legislative issues for 2019 and beyond.

Learn more and register:

www.bcan.org/2018-Leadership-Summit



Inspiring Excellence in the Bladder Cancer Community

FRIDAY, OCTOBER 12 – SATURDAY, OCTOBER 13, 2018 | HOUSTON, TX



RESEARCH



ADVOCACY



EDUCATION

A two-day conference to educate, engage, and energize patient advocates.