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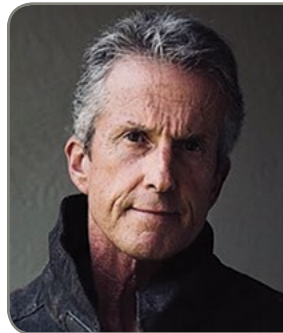
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San Francisco Firefighters in New York after 9-11. Dan Armenta the third firefighter from the left, died from bladder cancer in 2013.

The Truth About Firefighters and Bladder Cancer



Retired firefighter Captain Tony Stefani started with the San Francisco Fire Department in 1974. The 28-year veteran retired as the Captain of Rescue 1 in 2003. After being diagnosed with transitional cell carcinoma in 2001, he founded the San Francisco Firefighters Cancer Prevention Foundation and now serves as its President.

I WAS THE CAPTAIN at Rescue One in San Francisco, one of the busiest firehouses in the United States where rest is something you don't often get. Keeping in top physical condition was very important.

In January of 2001, I went out for a morning run. As I headed back to the gym, I reached a point where I could barely walk. I was exhausted and just did not feel right. When I got back to the gym restroom, I urinated only blood, gross hematuria. I immediately went to my physician with a sample, and within a few days, I had an ultrasound which detected a mass in my right renal pelvis, up in my kidney. They tried to reach the tumor but could not, so I was referred to my surgeon, Dr. Marshall Stoller at UCSF. It turned out to be transitional

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...



During May, in more than 25 cities across the U.S., patients, survivors, families, caregivers, doctors, healthcare providers, and others joined BCAN to raise awareness and much-needed funds for bladder cancer education, awareness and research.

Through BCAN's Walk to End Bladder Cancer events, courageous patients and dedicated volunteers truly make a difference in the fight against bladder cancer. This year through our annual Walks, we expect to raise more than \$800,000 for bladder cancer research and educational programs, thanks to the efforts of more than 3,000 caring people like you.

Bladder cancer awareness activities are global because bladder cancer does not recognize borders. Our counterparts in Australia, Canada, the U.K., and other countries are also raising funds and raising awareness. In 2019, BCAN joined our patient advocate partners in Barcelona as a founding member of the World Bladder Cancer Patient Coalition. You can read more about that meeting in this issue.

Better education and awareness of bladder cancer saves lives.

BCAN was founded for patients and their advocates. They are at the heart of our work. I encourage you to join us in Baltimore at our Bladder Cancer Patient Summit on October 4-5, 2019 for a meaningful two days when we will share resources, stories and memories.

Many of you have told us that our Patient Stories — both on the website and in issues of *The Beacon* — are not only helpful, but inspirational. Consider telling your story too! You can share your story by visiting www.surveymonkey.com/r/MyBCStory or by calling our office at **888-901-BCAN**.

Finally, did you know that BCAN now has a monthly, electronic newsletter? The BCAN Bulletin is interactive, delivered via email monthly and is filled with links to additional resources. Consider subscribing today at www.bcan.org/newsletters.

Sincerely,

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

Andrea Maddox-Smith
Chief Executive Officer

P.S. I look forward to communicating with you and I welcome your ideas and thoughts. If you would like to reach me via traditional mail, you can use the enclosed envelope, or contact me at BCAN at 301-215-9099, or via email at amsmith@bcan.org.

New Discoveries Research Lecture & Luncheon 2019

For the third consecutive year, BCAN was hosted by the Palm Beach Florida community to present a discussion and networking event on bladder cancer treatment innovations. The New Discoveries Research Lecture & Luncheon brought experts from academia and the federal government for presentations and conversations on March 6, 2019.

The 2019 symposium featured John Gore, MD, Associate Professor from the Department of Urology at University of Washington School of Medicine; Seth Lerner, MD, Professor of Urology at Baylor College of Medicine, and Andrea Apolo, MD, Chief of the Bladder Cancer Section of the Genitourinary Malignancies Branch at the National Cancer Institute. After their presentations, BCAN's Co-Founder Diane Zipursky Quale led a panel discussion and facilitated questions from the packed room.

BCAN Board members Mary Gushée and David Pulver co-chaired the event, and money raised will fund the Palm Beach Young Investigator Award.

BCAN expresses deep gratitude to the Palm Beach Community for this well-received awareness event.



Dr. John Gore, Dr. Andrea Apolo, BCAN Co-Founder Diane Z. Quale, and Dr. Seth Lerner shared recent advances in bladder cancer research.



Honorary Chairs, David & Betty Scaff



Event Co-Chairs, Mary Gushée and David Pulver with BCAN Co-Founder, Diane Zipursky Quale

Special Thanks to the Sponsors of the 2019 New Discoveries Research Lecture & Luncheon

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> *Continued from front cover*

cell carcinoma. Because it was located in my kidney, it was considered Upper Tract Urothelial Carcinoma (UTUC). On March 27, 2001, I had a radical nephrectomy (removing the kidney entirely).

That's my bladder cancer story. Of course, I had a follow-up every three months with cystoscopy for about two years. Eventually, they were spaced further and further apart. After 12 years, my surgeon said, "Okay, we're at the point now where you're basically cancer free. Go out and live your life." And that's the way I am now. I'm going on 18 years after my diagnosis and surgery.

Within two years after I was diagnosed, another firefighter came down with transitional cell carcinoma. There were five of us at Station 1 with bladder cancer. Two of us had UTUC transitional cell carcinoma in the renal pelvis, and the other three had bladder cancer. Only two of us are still alive.

When I started in the Department in 1974, we very seldom wore self-contained breathing apparatus while fighting fires. As years went on in the mid-eighties, California OSHA made it mandatory that firefighters wear self-contained protective breathing equipment (SCBA's) at working fires which is basically compressed air. We wore SCBA's when we were fighting fires, but during the overhaul process, after the fire was out, they were taken off.

Unfortunately, the overhaul process is probably the most toxic time because these products of combustion are "off gassing" various chemicals, different polymers and everything that they're made up of. We were all exposed to suspected toxic carcinogenic chemicals.

My doctor explained, "Okay you got a kidney, that's a filtering system. It is not going to completely eliminate some of these carcinogenic properties that firefighters face. When the carcinogens come in contact with the urothelium, the tissue lining the bladder and the renal pelvis of the kidneys, there is a possibility of getting a mutation in your genes, and somewhere down the line contracting some form of cancer." And that's what's been happening to many in our line of work.

The culture of my profession is changing now because of greater awareness of the high rates of cancer in firefighters and other first responders – bladder and kidney cancer being two of them. Now with the turnout coats and the bunker gear that firefighters wear on the job, we take steps after working a fire we call gross decontamination. This is where firefighters are basically washed off with a hose. Firefighters get back on their rig to go back to quarters, and their equipment is cleaned.

In San Francisco we have invested in \$8,000 heavy duty washing machines to extract these toxins. While contaminated clothes are being cleaned, the firefighter now wears a second set of clean turnout gear. In the old days, I probably washed my turnouts maybe three times in 28 years. I never cleaned up. When you're around other fire companies, the guys who were the filthiest were held in the highest esteem because it was thought "those are the guys who were fighting all the fires."



Retired San Francisco Station One Captain Tony Stefani.



This year, go for great.



Make your generosity permanent with a legacy gift that endures for generations.

Contact us or visit our website for more information.

Anita Parker
Director of Planned Giving
301.215.9099 ext. 202
aparker@bcan.org

Have you already left us in your will or estate plan? 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.

Do you want to make a significant gift that will transform the future of the Bladder Cancer Advocacy Network for generations to come?

You can do it today—with a legacy gift such as:

- » Making a gift through your will or trust
- » Giving life insurance you no longer need
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bcan.plannedgiving.org | 301.215.9099 ext. 202



Captain Tony Stefani (second from left) and members of the San Francisco Station One Fire Department.



China Basin Pier Fire 1991, Tony Stefani on the right.

Fortunately, this culture is slowly changing in a positive direction. The days of firefighters keeping their turnouts without cleaning them are rare because firefighters are more aware of how important it is to have this equipment clean. That old way is behind the times because new information is available, not only to major metropolitan areas but also to small departments with volunteers, which makes up the most significant number of firefighters. The word about carcinogenic dangers on work clothes is out and is benefitting those on the job today.

However, standard operating procedures are not uniform across the United States. Every department has its own practices in place. In San Francisco, the operating procedures have been standardized in the last few months. Our San Francisco Firefighters Cancer Prevention Foundation (SFFCPF) has pushed for standardization for nearly 13 years. It has taken this long for the administration to make this change.

Even now, there are hardheaded folks out there who say, "Hey, I'm fine. I can take the smoke,

About the Firefighters Cancer Presumptive Law

Many states cover firefighters for one or more cancers under workers' compensation because of presumptive legislation. This presumptive legislation contains broad or nonspecific language that can be interpreted to cover any cancer experienced by a firefighter. Most commonly those are leukemia, non-Hodgkin lymphoma, brain cancer, bladder cancer, and gastrointestinal cancer.

San Francisco adopted this law in 2014, after one of the studies that they were involved in with the Center for Disease Control's National Institute for Occupational Safety and Health (NIOSH). NIOSH sent out three epidemiologists to San Francisco in 2010 to see if there was a direct correlation between firefighting and elevated rates of cancer. The law is nationwide, but it's up to each municipality to adopt it.

Find out if your state has adopted this legislation: www.FirstResponderCenter.org/cancer/toolsresources/presumptive-legislation-firefighter-cancer-state/

there's nothing that's going to bother me or hurt me." They come to the realization that they've made a big mistake when they get sick or when a good friend from their station gets sick.

I was motivated to start the SFFCPF because of the number of individuals with cancer at the firehouse where I worked. When I was sick, San Francisco did not have the Firefighters Cancer Presumptive Law in place. It was tough for me to prove that I got cancer because of the exposures I had on the job. We are not human guinea pigs, but the cities' workers comp division wants you to explain why you think your cancer was job-related.

After they removed my kidney and while I recuperated, I had used up all my sick and vacation time. I got to a point where there was no income. I was a Captain at the time. There were 200 officers in San Francisco, and each of them donated one day of leave time to me. That was over a year's worth of actual service time. Their generosity made sure I had a paycheck



Tony Stefani and his grandchildren.

until I got to the point where I was able to retire. There was no way I could monetarily pay that back. This Foundation is a way for me to say “thank you” to those who helped me during my time of need. The SFFCPF has been dedicated to the detection and prevention of cancer for both active and retired firefighters since 2006.

We’ve been very successful at making changes in the firefighter culture by providing funding for various science-based studies that show the direct correlation between our job and elevated rates of cancer. We also identified 12 of our firefighters, both active and retired, through our bladder cancer screenings, who did not know they had cancer.

We are now able to fund genomic testing for firefighters. We pay up to \$3,000 to have their tumor genomes profiled to see if there

is a targeted therapy for their particular type of cancer. We pay up to a \$1,000 for second opinions. We also provide some travel expenses for a San Francisco firefighter and his/her family, to travel to a top-notch cancer center for a type of treatment that may not be readily available here.

We have no paid employees; nobody makes a penny. We now have cancer navigators that will help a firefighter who is diagnosed. The navigator can tell them the studies that we’ve been involved with and the doctors that we recommend for second opinions and what direction we think they might want to investigate.

I hope those reading this article come to the realization of how dangerous our profession is, not only the possibility of being killed at a working fire but also the greater than one in two chance of getting sick at some point. Would I do it all over again? That is easy to answer, absolutely! It truly is the greatest job in the world.

Pay it Forward: Share this issue of “The Beacon” with your local fire station.

When you finish reading your edition of “The Beacon”, why not drop it off at your local fire station? Help BCAN share this important poster and inspiring story with the first responder community.

Dr. Marshall Stoller is Fanning the Research Flames for Firefighters with Bladder Cancer



*Dr. Marshall Stoller**

“It is not just active firefighters but retired men and women who are at risk. Because the exposure may take years to develop into a tumor early detection remains key. Firefighters are saving people every day. The least we can do is to help them out, recognize the potential risk/s and try our best to detect these potential tumors early when they remain curable” notes Dr. Stoller.

When Tony came to my office, his doctors thought he had a filling defect in his right renal pelvis. I initially thought it could be some kind of blood clot, perhaps a kidney stone, or a tumor from the lining of the kidney. After we examined him, we determined that indeed it was a tumor. In that situation, we needed to remove his kidney and attached ureter, all the way down to the bladder. Because whatever caused the tumor in the renal pelvis could also cause it in the ureter, in the bladder or even the other



BCAN[®]

Bladder Cancer Advocacy Network

Leading the way to awareness and a cure





THE TRUTH ABOUT

FIREFIGHTERS AND BLADDER CANCER

Exposure to carcinogens puts firefighters at risk for bladder cancer. Bladder cancer can be beaten if detected early. Know the signs.

SIGNS AND SYMPTOMS

Bloody or discolored urine

Changes in urination including frequency and urgency.

At first sign, see your doctor.



More information: www.BCAN.org or 888-901-BCAN (2226)

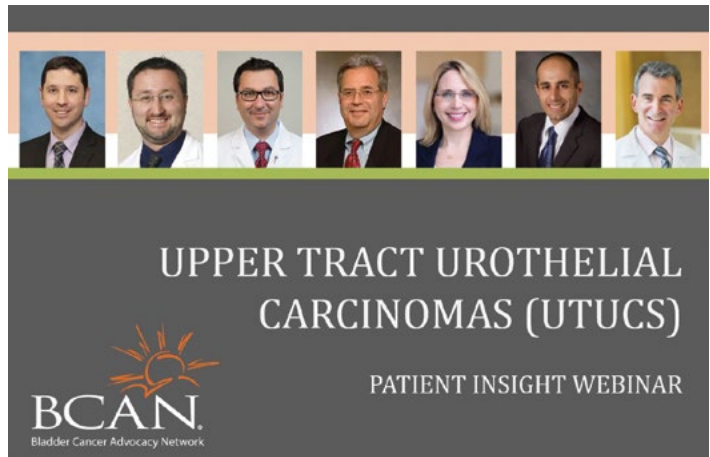
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kidney; it is a field defect potentially effecting all areas of transitional cell lined tissues.

Tony did have what we call Upper Tract Urothelial Carcinoma (UTUC) or transitional cell carcinoma in his right renal pelvis. Over the years we followed him with periodic cystoscopies to rule out potential subsequent tumors in the bladder or remaining kidney, which can happen. Tony was lucky that we were able to catch this tumor early. There is no effective chemotherapy or radiation therapy for UTUC. The treatment of choice is to surgically remove his kidney and ureter – a nephroureterectomy.

After I saw Tony and a few other firefighters in my practice, I realized firefighters appear to have an increased instance of the urothelial carcinoma. We started screening San Francisco firefighters. There appears to be a dramatic increase in the instance of bladder cancer in firefighters. The question is why? And why is it happening now? Why didn't it happen 50 years ago? I think the types of fires they are fighting today are markedly different than just a wood fire, due to all the “bad stuff” in our computers and other electronic devices with all the plastics and other unknown heavy metals. First responders are exposed to this different type of smoke. Exposure to smoke and those toxins just doesn't happen during the fire but continues after, when personnel are trying to figure out the source of the fire. It's hard to wear a mask all the time, especially when it is hot and humid.

And the questions that we've been looking at in the laboratory are: how long is it safe for a firefighter to fight these contemporary fires? Are there other things that we should do to protect firefighters' kidneys and bladders from these toxins? When you've been around a campfire, your clothes smell like smoke from the fire. This is a significant concern for firefighters because the smoke contains many chemicals. Companies are trying to figure out how to decontaminate a firefighter once they return to the firehouse. Not only is cleaning their clothes necessary, but they now have the option to go into a sauna to try to get them to sweat to try to remove all the toxins out of their bodies; it appears that this may be helpful.



Visit: www.bcan.org/utuc-bladder-cancer/

Watch this webinar to learn more about UTUC

With the recent large-scale fires in California, many commercial and residential buildings have burned. In Paradise, CA, they found a lot of benzene in the water supply after these fires. Each firefighter was likely getting exposed to these toxins during the firefight. There is an opportunity to reduce those risks. Are there better types of masks to wear for protection that can be more comfortable in extreme temperatures?

Tony is lucky because he came to the attention of a physician right away. We caught his UTUC early. We had the surgical expertise to remove his effected kidney and ureter. There continues to be a need to develop new techniques to screen at-risk individuals, specifically firefighters who are at risk for these types of tumors. We want firefighters to know, if they feel like something is different, if they see blood in their urine, even one time, they need to see their physician. Sometimes you can't see blood in the urine, and in those situations the doctor can check for microscopic blood with a dipstick or microscopy techniques as an easy screening test. Blood in the urine is abnormal. It needs to be thoroughly evaluated. The key to this kind of tumor remains early detection and appropriate intervention.

**Dr. Marshall L. Stoller is a urologist at UCSF Medical Center*

World Bladder Cancer Patient Coalition Launched in Barcelona

For the first time ever, people affected by bladder cancer – the fifth most common cancer in the Western world, with more than half a million new cases reported every year — will have a global voice, the World Bladder Cancer Patient Coalition (WBCPC). BCAN is proud to join with our neighbors to the north, Bladder Cancer Canada and across the pond, Fight Bladder Cancer U.K., as founding members of the WBCPC. Launched in Barcelona, Spain this past March at the European Association of Urology meeting, WBCPC members now include:

- Action Bladder Cancer U.K.
- Bladder Cancer Australia Charity Foundation
- Les Zuros (Bladder Cancer Support Group France)
- PAzienti Liberi da Neoplasie UROteliali (PaLiNUro, Italy)
- Blærekreftforeningen (Norwegian Bladder Cancer Society)



Stephanie Chisolm, BCAN's Director of Education and Research at the WBCPC launch with Dr. Piyush Agarwal of the NCI and Dr. Trinity Bivalacqua from Johns Hopkins Medical Center.

“This Coalition unites patients around the world, giving them a powerful voice in the fight against a lethal disease that significantly impacts not only their survival but also their quality of life,” adds Piyush Agarwal, of the National Cancer Institute. “The World Bladder Cancer Patient Coalition aims to create a global voice that hopes to alleviate much of the pain and suffering associated with bladder cancer.”



Members of the WBCPC at the organization's launch in Barcelona, Spain.

“Treatment, research and support for bladder cancer patients varies widely across the globe and even within countries,” said Ken Bagshaw, the current President of the WBCPC. “It’s critical that we mobilize bladder cancer patient organizations across the world to help ensure the best possible outcomes for patients.”



BCAN wants to hear YOUR voice in choosing important research questions and designing research that provides direct benefits to patients through the bladder cancer patient survey network. Visit www.BCAN.org/bladder-cancer-patient-survey-network to learn more.

2019 Bladder Cancer Summit for Patients and Families



“The Summit enhances our coming together, sharing our stories and supporting each other.”
— 2018 Summit Participant

Imagine being in a room with filled with people who really do know what you are experiencing on your bladder cancer journey...

Join BCAN October 4-5, 2019, at the Westin Baltimore Washington International (BWI) Airport in Maryland for our fourth annual Bladder Cancer Summit for patients and families. The

“Awesome to hear from care providers and I am thankful for those who have blazed the trail and filled it with hope!”
— 2018 Summit Participant

Summit engages, educates and energizes bladder cancer survivors and their families.

- Participate in the discussion of current and upcoming advances in bladder cancer treatment with Drs. Gary Steinberg, Arjun Balar and Armine Smith.
- Be part of the conversation about caring for bladder cancer caregivers.
- Learn about engaging in bladder cancer research.
- Help us recognize our outstanding volunteers at our *Best of BCAN Awards* reception.

Registration is now open. Visit support.BCAN.org/BCSummit or call us at **888-901-2226** to register now.

Join Us for the Bladder Cancer Summit For Patients and Families **October 4–5, 2019 in Baltimore, Maryland**



Images from the 2018 Summit, held in Houston, Texas



Shining a Light on Bladder Cancer Around the Country

Several volunteers helped BCAN by reaching out to building and landmark managers, asking them to “Shine A Light” on bladder cancer by illuminating their structures in May for Bladder Cancer Awareness Month.

Bladder cancer organizations around the world had buildings and structures illuminate in orange to spark conversations and raise public awareness about the symptoms, signs and risk factors of bladder cancer,” notes BCAN CEO Andrea Maddox-Smith. “The significance of the orange illuminated structures is to help ‘shine a light’ on the 6th most common cancer in America which is under-recognized by most people.”

Some of the buildings/landmarks that were illuminated in May included:

- Niagara Falls, NY: May 2nd
- PECO Building, Philadelphia, PA: May 6th
- The Peace Bridge, Buffalo, NY: May 7th
- Wells Fargo Duke Energy Center, Charlotte, NC: May 8th
- Seattle Great Wheel and Columbia Center Building, Seattle, WA: May 10-11
- The Naperville Carillion, Naperville, IL: May 13-20
- Baylor College of Medicine, Houston, TX: May 13-20
- Pennsylvania State Capital Building, Harrisburg, PA: May 20-26

“Be the light that helps others see.”

— Anonymous



Pennsylvania State Capital Building, Harrisburg: May 20-26



The Peace Bridge, Buffalo, NY shining #BCANOrange in May.

BCAN Chapters Corner

Want to get active with your local bladder cancer community? Learn more about what the BCAN Chapters do and how to get involved at www.BCAN.org/Chapters. Chapters are located in:

- Albany, NY
- Corpus Christi, TX
- North Carolina Triangle
- Pennsylvania
- Richmond, VA
- San Diego, CA



The BCG Shortage: Why It Matters

What Is BCG?

Bacille Calmette Guerin (BCG) is a treatment that many non-muscle invasive bladder cancer patients rely on. It was initially developed for vaccination against and prevention of tuberculosis. Important discoveries were made in the 1950s indicating some animals were resistant to tumor growth after being given BCG. Scientists learned that BCG needs close contact with the tumor to be effective. In the 1970s, a doctor from Canada performed the first human trial, putting BCG directly into the bladder using a catheter. The FDA approved BCG to treat bladder cancer in the 90s. BCG reduces recurrence and progression of cancer.

Producing BCG is complicated. It contains a weakened, but live bacteria. Manufacturing requires a three-month growing period with precise temperatures and ingredients for safe and optimal growth. Only one strain (TICE) is approved for usage in the U.S., Merck is the only company manufacturing TICE today. And that is a problem around the world. Though Merck has increased production, they've not been able to keep up with the demand.

BCAN and the BCG Shortage

As the voice of U.S. bladder cancer patients, BCAN is deeply concerned and involved with patients, doctors, industry, media, and governmental officials about the current shortage. Finding a short- and long-term solution is one of our highest priorities, which is why we have taken the following actions:

- BCAN met with key contacts at the Center for Biologic Evaluation and Research for the Food and Drug Administration (FDA). This office monitors and regulates drugs such as BCG. We are pushing the FDA and the medical community to find solutions to this shortage.
- As the voice of patients, BCAN met with Merck to strongly emphasize the impact the shortage is having on patients and doctors and their concerns.
- We convened a meeting of BCAN's Scientific Advisory Board, representatives from the American Association of Clinical Urologists (AACU), the American Urology Association (AUA), the Large Urology Group Practice Association (LUGPA), the Society of Urologic Oncologists (SUO), and the Urology Care Foundation (UCF) to develop strategies for healthcare providers until the shortage is resolved.
- We hosted a webinar led by medical experts and a patient advocate providing information about treatment options for patients. Watch now at www.BCAN.org/bladder-cancer-bcg-shortage-webinar/

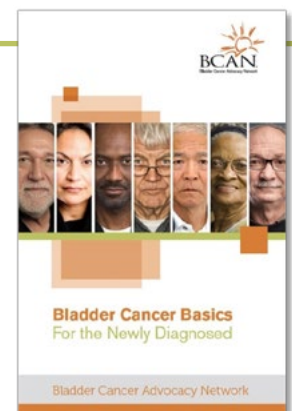
We are told that the current shortage will last throughout 2019 with no solid guarantees after that. Visit www.BCAN.org/2019-bcg-shortage-bladder-cancer/ for the latest information and updates on the BCG shortage.

Bladder Cancer Basics for the Newly Diagnosed

BCAN's handbook is available, free of charge, to help bladder cancer patients and their caregivers learn about their diagnosis and treatment options. With the help of their medical team, this resource will assist in making informed choices about continued medical care.

Available on demand at www.bcan.org or request a free copy.

www.BCAN.org/Handbook



THE BEACON READERSHIP SURVEY

1. What is your favorite part of The Beacon? (mark all that apply)

- Stories about patients and survivors
- Articles about research developments in bladder cancer
- Resources with information helpful to me
- Other_____

2. I like to receive my information from BCAN (mark all that apply)

- Electronically/Email
- Paper copy/Snail mail
- I'm OK with either

3. What would you like to see in future issues of The Beacon?

4. Name (optional)



Please clip this survey and mail in the envelope provided.

You can also answer the survey online at www.SurveyMonkey.com/r/TheBeacon



My Bladder Cancer Story

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

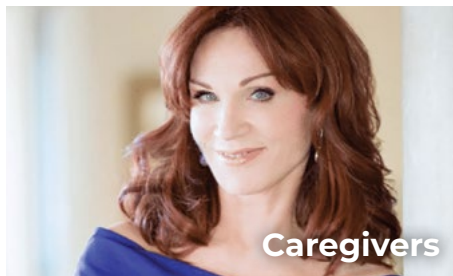
www.BCAN.org/my-bladder-cancer-stories



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Young Adults



Caregivers



Men



Leading the way to awareness and a cure

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#BladderCancerAware