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## Rick's Story: Surviving with Faith and Family

**R**ick was diagnosed with bladder cancer on June 24, 2022, at age 55. During his life, he maintained a healthy and active lifestyle. On Saturday morning, Rick discovered blood in his urine. He contacted his primary care physician, a retired nephrologist, and told him that he suspected that he had another kidney stone since he had two previously. Rick's doctor asked him how bad his pain was and he responded that he had no pain. Concerned, Rick's doctor said, "If you have no pain and have that particular symptom, then you have something else going on." Two days later on Monday morning, Rick went in for a CAT scan.



Rick

Everything looked fine on the scan of Rick's kidneys and his doctors recommended that he get a cystoscopy because they feared something was wrong. Rick told BCAN, "He let me know that he would feel better about my situation if I were doubled over in pain, but because I was not having pain and passing blood, it was cause for him to worry. When I look back, I am happy he did. The blood in my urine only lasted a few days, but I listened to him and took steps to figure this out."

### "Uh oh."

Rick was awake during his cystoscopy and found it fascinating to watch. During the procedure, Rick heard the urologist saying, "Uh oh." He asked Rick to look at the screen and was then told he was looking at a papillary tumor in his bladder. Rick said, "This was a shock for me. My first question was, is the tumor malignant?" His urologist took a sample of tumor for further observation and the test results confirmed that Rick had bladder cancer.

### Undergoing a TURBT

Rick's urologist recommended a TURBT (transurethral resection of bladder tumor) procedure, but he could not get the procedure for three weeks. Rick told BCAN that "...the waiting period was the worst part. I did not know what to

*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

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# A Note From Andrea...



It's hard to believe that 2022 has gone and that we are already well into the new year. I am excited about the new offerings that BCAN has in 2023 and would like to tell you about them.

As you'll read in the pages that follow, in January, we launched our first-ever Bladder Cancer Support Line staffed by trained oncology social workers. By calling **833-ASK-4-BCA (833-275-4222)**, you can speak with professionals who offer psychosocial support for bladder cancer patients, their loved ones and the bereaved.

In February, we will host the first of our monthly virtual support group meetings for women with bladder cancer. It will take place on the first Tuesday of the month and you can join us by scanning

the QR code on page 11.

During the second quarter of 2023, we will announce a free mobile device app for bladder cancer patients and caregivers. The app will offer a host of customizable features to help navigate this challenging disease.

In May, we celebrate our community during Bladder Cancer Awareness Month. We'll kick things off with a slate of in-person Walks to End Bladder Cancer as well as a Virtual Walk on May 6. Every step you take helps us work towards a world without bladder cancer. Don't forget to register to walk at [bcanwalk.org](http://bcanwalk.org).

During May, we'll also hold our annual Ask the Experts Zoom event in which you can submit questions to leading bladder cancer doctors in the United States.

For the first time ever, we will hold two Summits for Patients and Families. The first will be in Phoenix on March 30 and April 1 and the second in Nashville in the fall.

No matter what the year, I stand in awe of the patient, caregiver, researcher and medical provider heroes who continue to confront bladder cancer with courage and dedication. I hope that BCAN can continue to play a helpful role in your own journey.

I am always happy to hear your thoughts about BCAN as well as other topics related to our bladder cancer community. Feel free to email me at [amsmith@bcan.org](mailto:amsmith@bcan.org).

Sincerely,

Andrea Maddox-Smith  
Chief Executive Officer



## My Bladder Cancer Story

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

[bcan.org/stories](http://bcan.org/stories)



Women



Young Adults



Caregivers



Men

expect, and my anxiety was getting the best of me.” Immediately after his TURBT, Rick received a round of mitomycin C chemotherapy directly into his bladder and he was back home the same day. Rick added, “I am blessed that the cancer was caught early and I was able to keep my bladder.”



To learn more about TURBT, please see our fact sheet on the following two pages or scan the QR code to the left to visit BCAN's Understanding TURBT page.

## Keep an upbeat attitude

Rick is philosophical about his journey with bladder cancer. He recently told BCAN, “Many people diagnosed with bladder cancer often feel like it is the end. I want my story to be a testament that this does not have to be the end. You will have times when you are down and feel like giving up, but do not be discouraged.” Rick also said, “My advice to anyone reading this story would be to keep an upbeat attitude

## 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](https://bcan.org/S2S) and fill out the online form. You can also call **301-215-9099, extension 212** and leave a message.

and know that things will be alright. After my diagnosis, I spent four days feeling depressed and feeling sorry for myself until I thought about it and realized there were so many people who had situations worse than mine, and I had many things to be thankful for.”

For fellow patients, Rick added, “Be encouraged. There are so many advances in bladder cancer treatment.”

## Family and faith

Rick had a strong desire to share his story with the bladder cancer community to give encouragement to other patients and loved ones. He told BCAN that he relied heavily on others: “Thanks to my family and faith, they helped me stay strong. My family and friends smothered me with so much love. In moments when I was down, I would put on spiritual music to lift me. This journey is not one to an end but to a new beginning.” 



Scan this code to read Rick's and others' bladder cancer stories.



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.

## ► What is **TURBT**?

A transurethral resection of the bladder tumor (TURBT) is a surgical procedure used to diagnose and treat visible bladder cancer tumors. TURBT is often an outpatient procedure done in the hospital. Most patients go home the same day, but some may stay in the hospital overnight because of their medical conditions or the extent of the tumor resection.

## ► How is **TURBT** done?

The doctor inserts a resectoscope through the urethra to examine the bladder more completely while the patient is under anesthesia (general or spinal). The doctor then uses a small, electrified loop of wire attached to the resectoscope to remove bladder tumor tissue. A pathologist looks at that tissue to determine the stage and grade of the bladder cancer.

Your doctor may add a chemotherapy drug directly into the bladder after a TURBT to reduce the chances of future tumor recurrence.



### ASK YOUR HEALTHCARE TEAM

- *What will the results of the TURBT tell you?*
- *How long does the TURBT take?*
- *Will I likely need a urinary catheter when I go home?*
- *Will you give me any other treatments with the TURBT?*
- *How long should it take for me to recover after the TURBT?*
- *When will you know the results of the pathology report? How will you share those with me?*
- *What is your experience with the TURBT procedure?*
- *Will you be using enhanced cystoscopy during my TURBT?*

Always consider  
a 2nd Opinion 

## TERMS TO KNOW

- **Anesthesia:** Loss of pain and other sensation, using medication.
- **Biopsy:** The examination of tissue removed from the body to discover the presence, cause, or extent of a disease.
- **Catheter:** A flexible tube inserted through a narrow opening into a body cavity, particularly the bladder, for removing fluid.
- **Chemotherapy:** The treatment of cancer disease using chemical substances.
- **Cystoscopy:** Examine the bladder and urethra using a thin, lighted instrument (called a cystoscope).
- **Intravesical:** Within the bladder.
- **Pathology:** The laboratory examination of samples of body tissue for diagnostic purposes.
- **Pathologist:** A doctor who identifies diseases by studying cells and tissues under a microscope.
- **Resection:** To cut out tissue or part of an organ.
- **Resectoscope:** A thin, tube-like instrument used to remove tissue from inside the bladder with a light and lens for viewing.
- **Stage:** The extent of cancer within the body.
- **Urethra:** The tube through which urine empties from the bladder.

## WHAT YOU SHOULD KNOW: Advice from bladder cancer patients who have experience with TURBT

### BEFORE A TURBT

Bring a friend or family member to take notes on what the doctor tells you.

- Ask your doctor what type of anesthesia you will receive for your TURBT. Find out if there is anything you should do before your TURBT procedure.
- Ask your doctor about any pre-operative testing you may need, and where and when that testing will happen.
- Find out where your TURBT will take place and what to expect on the day of your procedure.

### DURING A TURBT

- The doctor cuts visible tumor(s) away from the lining of your bladder wall using instruments inserted through the resectoscope.
- Once a tumor has been removed, bleeding is prevented or reduced by using a mild electric current to cauterize (burn) the area where the tumor was.
- Tissue from the tumor will be sent to pathology to be evaluated.

### AFTER A TURBT

- Once the TURBT is over, you will be taken to the recovery room to allow the anesthetic to wear off. Your nurses will encourage you to drink plenty of water. Drinking water helps flush out your bladder.
- When you wake up after your TURBT, you may have a catheter in your bladder to allow your bladder to empty. Fluid may be added to wash out blood and debris from your bladder.
- A catheter may need to be kept in for several days if bleeding is persistent. If you are sent home with a catheter, make sure you understand how to use it and when it should be removed.
- Before going home, you will get instructions on post-TURBT recovery, and you may also get a prescription for medicines to take.
- Side effects of the TURBT may include painful urination, bladder irritation, frequency, and bladder spasms. Medications and soothing gels can help. Ask your doctor what he or she recommends.
- Blood in your urine and passing blood clots (from where they took out the tumors) can continue for a few weeks.
- Pads or protective underwear can help people who experience urine leakage after the treatment.
- Plan to rest and take it easy for a few days after your TURBT.
- Drink lots of fluids to help flush out debris and clots in your bladder
- Call your medical team if you have questions or something seems wrong.
- Be sure to ask for a copy of your pathology report; keep this with your medical record information.

### NEXT STEPS:

- Your doctor will help you decide what additional treatment you might need based on what the pathology report says.
- You may need to have a repeat TURBT in 2-6 weeks to completely remove the tumor or to get a deeper biopsy sample for the pathologist to examine.
- If you have small, low-grade tumors that have not invaded the lining of your bladder, a TURBT may be the only treatment you need. You will still need regular cystoscopies to make sure there is no recurrence.
- If the tumor has invaded the muscle wall, your doctor may recommend surgery or other treatments.
- It can be helpful to talk to someone who has experienced TURBT. Call the BCAN Survivor 2 Survivor program to connect with a volunteer who knows about having TURBT procedure. Dial 888-901-BCAN.

Visit [BCAN.org/bladder-cancer-TURBT](http://BCAN.org/bladder-cancer-TURBT) for more information.

## The Bladder Cancer Advocacy Network (BCAN)

*BCAN's mission is to increase public awareness about bladder cancer, advance bladder cancer research, and provide educational and support services for the bladder cancer community.*



[www.bcan.org](http://www.bcan.org)



[info@bcan.org](mailto:info@bcan.org)

888-901-BCAN (2226)

# Choosing a Urinary Diversion

In a recent two-part Bladder Cancer Matters podcast, host Rick Bangs sat down with Dr. Robert Svatek for a question and answer session about choosing a urinary diversion, something all radical cystectomy patients face. Dr. Svatek is professor and chair of urology at the University of Texas Health San Antonio. He provides state-of-the-art surgical options, including robotic assisted and open surgical approaches, as well as all available urinary diversion options.

**Rick Bangs:** Who is eligible for a urinary diversion?

**Dr. Robert Svatek:** Those eligible for a urinary diversion are patients who have disease that is confined to the bladder and where removing the bladder gives doctors a chance of curing the patient. There are also a set of patients who may benefit from bladder removal for palliative reasons. What I mean by that is, let's say we won't be able to cure them with bladder removal, but we might be able to significantly improve their quality of life by mitigating or getting rid of the side effects or complications that they are having as a result of having their bladder in place. For example, excessive bleeding from the bladder tumor, excessive urinary difficulty or pain as a result of problems with their bladder.

**Rick Bangs:** What choices do patients have for a urinary diversion?

**Dr. Robert Svatek:** The important thing is that patients have a choice in the matter. There are three different approaches and I like to break them up into continent and incontinent urinary diversions. Continent means that there's a capacity feature that's created by the diversion, meaning that there's a storage of the urine and that it's not leaking continuously. Incontinent would be that there's no storage of the urine. That the urine just flows naturally out of the body.

An incontinent diversion is often called an ileal conduit, such that the urine is flowing from the kidneys down the ureters to a small segment of bowel. Often the ileum is used, approximately 12 to 15 centimeters in length. And the urine flows through that segment of bowel, just like a conduit, kind of like a PVC pipe, and it flows straight out of the body.



Dr. Robert Svatek



Scan this code to listen to Part 1 of the "How to Choose a Urinary Diversion" podcast.

And in that situation, we use an appliance that is applied to the skin of the abdomen to collect the urine. So the collection of the urine in that situation is done externally through a bag. That's an incontinent diversion.

The other two options are where we use a larger segment of intestine and create a reservoir on the inside of your body where urine is stored, and you periodically empty that reservoir. Those are continent diversions. And there's two types that are commonly done. One is called a neobladder. Neo is another word for new. So it's like a new bladder. And the other one is often called an Indiana pouch or a continent catheterizable urinary diversion.

**Rick Bangs:** Is a neobladder a good choice for patients?

**Dr. Robert Svatek:** Usually when I have this discussion, patients will immediately gravitate to the neobladder because it seems more natural. It's like, "Well, you're just replacing my bladder. I want that one." Then I will say, "There's just two downsides and one of them is the nighttime leakage," and the way that I explain that is that the neobladder is very dependent on the urethral sphincter to maintain continence.

At night as you sleep, the urethral sphincter is relaxed and you will experience some incontinence and you'll


have to have some strategy to mitigate that. The other potential downside with the neobladder is that in some cases, it may not empty completely. If that happens, the patient has to be able to catheterize themselves in order to empty the neobladder. If they don't, if the neobladder is not emptying well, the urine just sits there and it could form stones, infections, back up and eventually lead to kidney damage. One of the turnoffs for some of my patients is the possibility of having to self-catheterize.

**Rick Bangs:** What should patients look for in a surgeon to remove one's bladder and how can they find that person?

**Dr. Robert Svatek:** There are a lot of factors to consider and I think there is good data that high volume hospitals are going to have infrastructure and techniques in place to mitigate complications. That said, none of us are immune to complications. A radical cystectomy has a high complication rate, even among those high volume hospitals with outstanding surgeons. Complication rates tend to be above 30%, but a lot of those are very minor complications and things that are very easily managed.

The second factor to consider when looking for a surgeon is what's feasible for you. Some patients drive a long distance to see a doctor at a high volume hospital, but is it worth it for the patient to drive this distance rather than going with a surgeon who's been taking care of him or her? Those are important

questions that need to be considered. The other key factor is the relationship you've developed with your urologist. Do you have a good relationship with him or her, do you have confidence in your surgeon that he or she will take care of you after the procedure? If a complication does arise, do you have confidence that surgeon to get you through it? It's not always about surgeons who perform a lot of cystectomies.

Also keep in mind that asking for a second opinion for a major operation like a radical cystectomy is not offensive to doctors. It is something that we encourage. 



**BLADDER  
CANCER  
MATTERS**  
PODCAST

PRESENTED BY BCAN  
BLADDER CANCER ADVOCACY NETWORK

If you enjoyed reading the summary of this podcast, you will love our more than 40 Bladder Cancer Matters episodes. Simply visit [bcan.org/podcasts](https://bcan.org/podcasts) to start listening.

## Exercise Your FreeWill

Did you know that only 30% of Americans have completed a Will? Each of us know it's something that should be done but many simply never get it done.

As a benefit for members of the BCAN community, we have partnered with FreeWill, a company that provides an easy online way for you to create your own Will – FOR FREE. FreeWill has been trusted by over 300,000 Americans to safeguard their futures.

To learn more, please visit [bcan.org/FreeWill](https://bcan.org/FreeWill)



# Bladder Cancer Events and Programs in 2023

BCAN has a host of exciting and informational activities happening in 2023 and we invite you to be part of them. Please visit our web site, [bcan.org](https://bcan.org), to learn more.

APRIL—MAY



## Walks to End Bladder Cancer

In-person and virtual Walks to End Bladder Cancer. Visit [bcanwalk.org](https://bcanwalk.org) to find a Walk near you or join us virtually on May 6, 2023.

APRIL—MAY



## Beacon of Hope Award

In April and May 2023, BCAN community members will nominate and choose that special person who has been a beacon of light in their bladder cancer journeys.

MAY



## Ask the Experts 2023

Our popular Q&A with leading bladder cancer doctors is back this year and will take place in late May.

MARCH & FALL 2023



## Summit for Patients and Families

March 31 and April 1, 2023 in Phoenix, AZ. Fall 2023 in Nashville, TN – TBD, details coming in April.





ALL YEAR

### Patient Insight Webinars

BCAN's popular webinar series brings information to your computer, tablet or smartphone. Please visit [bcan.org/webinars](https://bcan.org/webinars).



ALL YEAR

### "Bladder Cancer Matters" Podcast

Bladder Cancer Matters is a podcast by, for and about the bladder cancer community. Please visit [bcan.org/podcasts](https://bcan.org/podcasts).



ALL YEAR

### Treatment Talks

Live webinars that include expert physicians along with a patient who has undergone that very treatment.



ALL YEAR

### Coffee and Conversations

Online programs that feature presentations by community bladder cancer experts.

# New, Free Resource for the Bladder Cancer Community

Recently, BCAN announced the launch of a new, free call center for bladder cancer patients and loved ones. By calling **833-ASK-4-BCA (833-275-4222)**, callers will be connected with professional oncology social workers with specific expertise on issues affecting bladder cancer patients and their families. The call center's staff will address the emotional, practical and informational needs of the bladder cancer community including those who have lost loved ones to the disease.

Callers to the support line will receive assistance from trained oncology social workers offering emotional support, free publications, resource navigation services and referrals to online and print resources like workshops, webinars and fact sheets that provide up-to-date information about bladder cancer. Additionally, callers can find out if they meet eligibility criteria for financial assistance to help defray the cost of treatment.

This expansion of BCAN's support resources for patients and families has been launched in partnership with CancerCare. Founded in 1944, CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer.

Trained staff are available from Monday – Thursday between 10 a.m. – 6 p.m. ET and Friday between 10 a.m. – 5 p.m. ET.

Call today. 



Scan this code to learn more about the Bladder Cancer Support Line.

# Walk to End Bladder Cancer and Win Cool Prizes

We invite you to join us and thousands of others to walk and help end bladder cancer in the Spring of 2023.


More than 82,000 people are expected to be diagnosed with bladder cancer in 2023. Join us to support the patient, caregiver, research and medical professional heroes confronting this terrible disease.

Register and start now! The earlier you sign up, the more money you can raise to help patients and loved ones.

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

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

## Raise \$100 - Earn a T-shirt

By registering for a Walk to End Bladder Cancer and raising just \$100, you'll earn a 2023 Walk commemorative t-shirt. Every dollar raised helps BCAN provide even more free educational and support programs and fund lifesaving bladder cancer research. 



Scan this code to register for a Walk near you



# An Online Tool to Compare Bladder Cancer Treatments

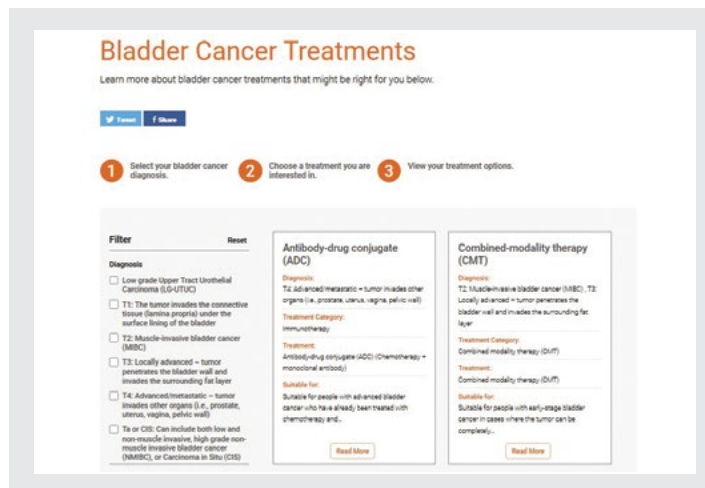
People who are already staggered by a bladder cancer diagnosis can sometimes feel confused and overwhelmed when discussing treatments with their medical provider. Patients who understand potential treatment options can make more informed decisions with their doctors.

To address this need, last year, BCAN launched a tool that enables patients and loved ones to peruse potential treatment options for them. Learning about feasible options is easy. Just:

- Visit [bcan.org/options](https://bcan.org/options)
- Tick a box selecting your diagnosis
- Choose the type of treatment you are interested in

Your prospective treatment options will appear on the screen. Click on the “read more” button and you can learn more about who it might be suitable for, how the treatment works, how it is typically used and administered and also read a complete list of potential side effects. From this page, you can also click on additional links to get even more information.

Using this tool, you can also find the link to bladder cancer clinical trials near you as well as a listing of National Cancer Institute, National Comprehensive Cancer Network and Veterans Administration treatment facilities in each of the 50 states plus the District of Columbia.



# New Virtual Support Group for Women




Scan the QR code on the left to save your seat in the Women's Virtual Support group.

We have often heard from women diagnosed with bladder cancer that they feel out of place in a urologist's office since it is usually filled with men. While bladder cancer has long been considered a disease of older men, studies have shown that women are more likely to present more advanced tumors at diagnosis and have poorer outcomes overall.

To address this need, BCAN has developed a monthly Virtual Support Group for women with bladder cancer. It takes place on the first Tuesday of the month and is hosted by women and for women.

We encourage talk about issues and concerns that are unique to women facing bladder cancer. Attendees can also meet others who truly know what each other is going through. The support group is moderated by nurse and BCAN patient advocate Karen Sachse, RN, MSN and Fox Chase Cancer Center social worker Miriam Pomerantz Kadosh, MSW, LCSW.

It's free to join us. To register, please scan the QR code above. 



*Leading the way to awareness and a cure*

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### Walk to End Bladder Cancer

Our annual Walks to End Bladder Cancer connect patients and caregivers and raise funds to help support bladder cancer patients and those who love them.

To register, visit [bcanwalk.org](http://bcanwalk.org) or text WALK to 1-888-901-BCAN (2226).

