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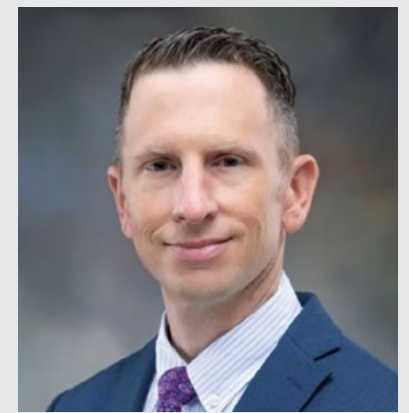
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Information about BCG and Bladder Cancer

In a recent episode of BCAN's "Bladder Cancer Matters" podcast, host Rick Bangs caught up with Dr. Robert Svatek to talk about the history of Bacille Calmette-Guérin, better known as BCG. Dr. Svatek is a Professor and Chair of Urology at the University of Texas Health San Antonio. He runs a cancer immunology lab. Dr. Svatek is actively involved in clinical trials for bladder cancer, including one on the Japanese strain of BCG.



Dr. Robert Svatek of the University of Texas Health San Antonio.

Which bladder cancer patients will typically receive BCG treatments?

Dr. Svatek: BCG is utilized for patients who are suffering from non-muscle invasive bladder cancer. BCG is often given for the superficial tumors that are more likely to recur after they've been removed. It may also be given to patients that have high-grade or high-risk features, and those features indicate that they have a fairly high chance of the tumor coming back after it's been surgically removed.

How is BCG administered?

Dr. Svatek: BCG is given intravesically, meaning that a catheter is placed into the bladder and BCG is instilled through that catheter in a solution of fluid water or saline. The advantage of this approach is that this facilitates immediate contact with the bladder mucosa.

How effective is BCG?

Dr. Svatek: BCG is extremely effective. It has been shown that BCG can decrease tumor recurrence or relapse by about 50%. In some patients who have a carcinoma in situ, or CIS, BCG can actually eliminate that tumor. Used as a treatment to eradicate CIS, it's highly effective. Eighty percent or more of patients with CIS will experience complete eradication of that disease with BCG treatment.

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.

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A Note From Andrea...



For me, spring is the time of year that brings the promise of renewal. When flowers emerge from their winter slumber, they remind me that there is always hope for a better tomorrow. As CEO of the Bladder Cancer Advocacy Network, or BCAN, this renewal also brings another opportunity to raise awareness of bladder cancer while supporting and advocating for patients and caregivers.

This year in May, Bladder Cancer Awareness Month, we are renewing our commitment to our community and beyond. It's the time of year for our Walks to End Bladder Cancer that raise funds and raise spirits to help defeat this terrible disease. In addition to welcoming back in-person walkers in more than a dozen cities, we will offer a virtual

Walk option on May 7, 2022 for those who prefer to participate on their own.

Also, our Virtual Ask the Experts event, benefiting our 2023 Young Investigator Awards research program will take place on May 25, 2022 at 7:00 pm ET. It is a unique opportunity for patients and caregivers to pose questions to two of the leading bladder cancer doctors: Gopa Iyer, MD, a medical oncologist from Memorial Sloan Kettering in New York and Sumeet Bhanvadia MD, a urologist at Keck Medicine at the University of Southern California in Los Angeles. The event is free, but registration is required. Please visit bcan.org/ask.

Hope and renewal are the focus of two patient stories in the pages that follow in this newsletter. The first is a story about a long-time survivor, 89 years young who had his bladder removed 25 years ago. The other story describes a patient who, after having her bladder removed, described herself as the "happiest ileal conduit person in the world."

In May and beyond, thanks to the generosity of our donors, we are also pleased to expand our educational offerings with several informative webinars planned as well as a map on our website that contains bladder cancer incidence rates, treatment and advocacy resources for all 50 states plus the District of Columbia.

I sincerely hope that springtime brings a sense of renewal and hope for you, too. With more than 720,000 people living with bladder cancer in the United States, hope is often the thing that is needed most.

I am always happy to hear your thoughts about BCAN as well as other topics of interest to the bladder cancer community. Feel free to email me at amsmith@bcan.org.

Sincerely,

Andrea Maddox-Smith
Chief Executive Officer



Walk with BCAN

Download our app to send messages and check your fundraising progress on the go from your phone or tablet.



How does BCG compare to chemotherapy?

Dr. Svatek: BCG has been compared to chemotherapy in multiple different trials in which both are given intravesically - through a catheter placed into the bladder. In almost every scenario in every clinical trial that we've seen, BCG outperforms chemotherapy.

In your opinion, why is there a BCG shortage?

Dr. Svatek: Before, we had two companies that were making BCG, two different strains. One was Merck, which makes BCG TICE, the other company was Sanofi Pasteur, which made the Connaught strain. Unfortunately, Sanofi Pasteur ceased production of the Connaught strain. While the details of what happened are not clear, there were some requests made by the U.S. Food and Drug Administration (FDA) to Sanofi Pasteur for reaching certain standards in the production facility in order to continue manufacturing the strain. The company decided that it was not in their best interest to produce it. So, they ultimately stopped the production of the Connaught strain.

When Sanofi Pasteur got out of the BCG business, that left Merck as the only company producing BCG for all needs, including those who were dependent on the Connaught strain.

The other part of this is that you can't just take another strain into the U.S. and start producing it. Any new strain needs to be approved by the FDA. The only strain that is approved for use and in production is TICE. Connaught is also approved and there's another strain called Armand-Frappier that is not in production anymore. So even though we have other strains that are utilized in the rest of the world, in Europe and in Asia, those companies can't just come to the U.S. and sell their product because they don't have FDA approval.

If you like this interview, you will love the more than 20 episodes of the Bladder Cancer Matters podcast. Simply visit bcn.org/podcasts to start listening.

What do we know about Merck's plans regarding the TICE strain?


Dr. Svatek: Merck has done a tremendous job of trying to provide BCG. They are, as I understand it, planning to build another production facility to help meet the U.S. demand.

As a patient, what do I do if I cannot get BCG?

Dr. Svatek: I think the most important thing is to have a discussion with your urologist to see how important it is that you get BCG. While there are multiple different types of patients that would benefit from BCG, some need it more than others. For some patients, there are suitable alternatives. One step is to just have a discussion [with your doctor] and ask, "How critical is it [that I have BCG treatments], given my bladder cancer state, and what alternatives are there?"

I have had patients that have come from other urologists where they were not able to access BCG and have been able to get BCG treatments in my practice. There are situations where one doctor's office may have it and another nearby may not. It is appropriate to ask around, check with another urologist, and check with a different facility to see if it may be available. It's good to know that BCG is the same in terms of its quality, whether you get it in city A or city B; it's all made from the same manufacturer.

Can BCG be transferred from one practice to another?

Dr. Svatek: It can. We've transferred it. With that said, if I have a limited amount for my patients, it's going to be difficult for me to transfer it out to another city or another urologist. 



Host of the "Bladder Cancer Matters" podcast and BCAN patient advocate, Rick Bangs

Vicki: I Think I am the Happiest Ileal Conduit Person in the World

Vicki had years of bladder pain before having a radical cystectomy in 2017. She says that from the moment she woke up from her surgery, she felt instantly better. She considers herself to be the happiest person in the country to have an ileal conduit.

In years past, Vicki dealt with tremendous pain, as if she had a urinary tract infection 24/7. During her appointment with the gynecologist, he said, "I fear you have a terrible disease called interstitial cystitis." Interstitial cystitis causes pain and pressure in the bladder area, often without having an infection or other clear causes.

Her bladder pain and sense of urgency to urinate was severe. She told BCAN, "I was mostly housebound, and if I did go out, I had to figure out ahead of time where to urinate because I was going to the bathroom about every 12 minutes. My bladder couldn't hold very much urine anymore. It was in such bad shape. Everything I ate and everything I drank made it hurt."

From interstitial cystitis to bladder cancer

After an episode of blood in her urine, Vicki went to see her doctor who said, "I fear you have bladder cancer." Reacting to this, she said "Whoa, aren't we jumping a lot of steps here?" The next step was to see a urologist, where she underwent a cystoscopy. During the procedure, the urologist saw three different presentations of urothelial bladder cancer. He performed a trans urethral resection of a bladder tumor, also known as a TURBT, and later a follow up procedure to attempt to remove the tumors. Vicki told BCAN, "My doctor told me we would do immunotherapy, BCG treatments, and that, if it didn't work, I would have to have my bladder removed. That's a daunting thing to hear."

Pain from the BCG treatments

Vicki underwent four BCG treatments and two were "excruciating" for her, telling BCAN "That last time, I remember sitting on my bed, and just crying, and

saying, 'What have I done to deserve this, that this should happen in my life, that I would have to go through such terrible pain?' That's when she told her doctor, 'I'm done with the BCG and I'm ready for the cystectomy.'"

Her urologist was supportive and said, "You've given it a valiant effort. Let's move ahead." In March of 2017, she had her bladder removed, opting for an ileal conduit. An ileal conduit is a form of urinary tract reconstruction which utilizes a small piece of intestine called the ileum. Urine drains into a small pouch that fits over the stoma and attaches to the skin with an adhesive. Vicki said, "I think I am probably the happiest ileal conduit person in the world. I got rid of that terrible pain. It was just gone from the moment I woke up from the surgery."

Vicki's road to recovery

While Vicki felt that her recovery from the surgery was slow – for a month, even standing to brush her teeth was taxing – she began to feel better with each passing day. She told BCAN that her surgery was in mid-March, and that on Memorial Day, she walked nine miles and at "a pretty good pace."

Without her bladder, Vicki opted to use an external bag, telling BCAN "I love wearing the bag. I wear the same clothing. I've never had a big leak. I've had a few times, over these four years, four-and-a-half years, where I have felt like, 'I feel a little damp. Am I sweating?' And then, I just change the bag."



Vicki S.

Continues on page 7 >

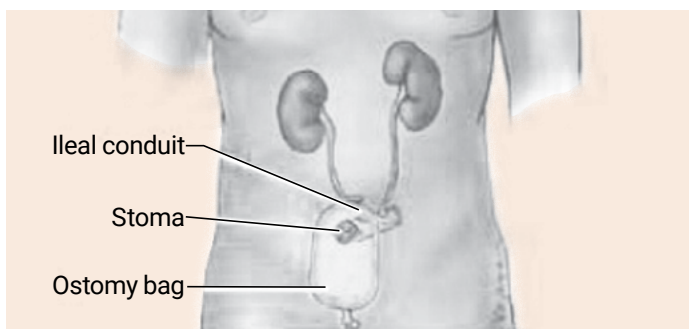
► What is an *Ileal Conduit*?

An ileal conduit (IC) is the most common **urinary diversion** performed by **urologists**. It is a simple form of urinary tract reconstruction that uses the **ileum** as an alternative pathway for urine to exit the body. The IC does not store urine. It is a way to remove urine from the body.

► How is an Ileal Conduit created?

After a **radical cystectomy**, a urinary diversion allows urine to leave your body. To create an ileal conduit:

- One end of a short segment of the small intestine (which has been removed from the rest of the intestine) is connected to a **stoma** that is created in the abdomen. Since a stoma does not contain any nerve endings, it is not painful.
- The **ureters**, which normally carry urine from the kidneys to the bladder, are attached to the other end of the segment of intestine.
- Urine travels from the ureters into the newly formed ileal conduit, through the stoma and out of the body.
- An **ostomy** appliance is placed over the stoma. This appliance consists of an adhesive skin barrier (wafer), which sticks to the skin surrounding the stoma and a pouch or bag that attaches to the skin barrier. This bag collects the urine and is worn outside the body. There is a twist valve at the bottom of the bag to conveniently drain urine as the appliance fills.



ASK YOUR HEALTHCARE TEAM

- » *Why is getting an ileal conduit a good option for me?*
 - **What are the benefits and risks of the ileal conduit?**
 - **Where will you put the opening for the bag (the stoma)?**
- » *What is your experience with ileal conduit urinary diversion?*
- » *What should I expect after my surgery?*
 - **What symptoms or side effects should I look out for?**
 - **How do I choose what supplies to use? Where can I buy supplies?**
 - **How will the bag affect my lifestyle? Is there anything I will not be able to do?**

Always consider
a 2nd Opinion



TERMS TO KNOW

- **Chemotherapy:** The treatment of cancer disease by the use of chemical substances.
- **Ileum:** A small piece of the small intestine.
- **Ostomy appliance:** A plastic appliance placed over a surgically created hole that lets waste leave the body.
- **Ostomy nurse:** Specializes in helping patients with ostomies.
- **Radical cystectomy :** Removal of the bladder.
- **Stoma:** A surgically created opening on the body to remove urine.
- **Ureter:** The tube that carries urine from the kidney to the bladder.
- **Urinary diversion:** A new way for urine to go from the kidneys out of the body created using a part of the intestine.
- **Urologist:** A doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs in males.

WHAT YOU SHOULD KNOW: Advice from bladder cancer patients who are living with an ileal conduit

BEFORE YOUR ILEAL CONDUIT SURGERY



- A portion of your intestines will be used to create the urinary diversion. Your surgeon will provide you specific instructions to prepare your intestine for your cystectomy.
- Ask your doctor about any special preparations you should follow before your surgery. These can include:
 - Medication or herbal supplements you should avoid or stop taking
 - Food and drink limitations
- Talk to your **ostomy nurse**. He or she can:
 - Help you decide where you want the stoma to be. When you decide where you want your stoma to be, think about how it will affect what you can wear.
 - Teach you how to change the bag and clean the skin around it.
 - Give you advice on what ostomy supplies you might want to try.

AFTER YOUR ILEAL CONDUIT SURGERY



The ileal conduit urinary diversion takes the least amount of time in surgery and uses the least amount of small intestine. Many patients have a faster recovery than with other diversion options.

» *With care, you can avoid a lot of problems.*

- Surgery can cause swelling, so the size of your stoma will shrink as you recover after the surgery. As you recover, make sure your ostomy supplies still fit.
- Make sure your clothing is comfortable. After you heal, most people are able to wear the same clothing they wore before their surgery.
- Leaks will still happen sometimes. Keep extra supplies in your car, at work, and when you travel, in case you need to change your bag.
- Once your stoma heals, if you notice bulging that is uncomfortable or makes it difficult to secure your ostomy appliance, speak to your urologists.
- Talk to your ostomy nurse if you have issues with leakage or irritation with your bag.
- Maintaining your ileal conduit will become a routine part of your everyday life.
- A urinary tract infection (UTI) can occur. Watch for stronger smelling, cloudy, darker urine or blood in your urine. A UTI may also cause lower back pain. Contact your urologist if you suspect you have a UTI.

SUPPORT IS IMPORTANT

- Talk to your family and friends about the bag. Do not hesitate to ask them for help when you need it.
- You can find more information about ostomies by visiting the United Ostomy Associations of America website, www.ostomy.org or calling (800) 826-0826.
- Ostomy companies will send you samples of supplies so that you can try them out and see which ones you like best. They also have ostomy nurses who can answer your questions.

NEXT STEPS:

- You will need occasional blood tests to check your body salts and kidney function.
- You will also need occasional abdominal imaging to confirm the cancer has not returned.
- You will still need regular checkups to make sure the cancer has not spread.
- Your doctor may recommend **chemotherapy** to help prevent the cancer from spreading.
- It can be helpful to talk to someone who has experience with an ileal conduit. Call the BCAN Survivor 2 Survivor program to connect with a volunteer who knows about having an ileal conduit. Dial 888-901-BCAN.

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.



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“How lucky am I?”

Through surviving years of painful interstitial cystitis followed by bladder cancer, Vicki is philosophical about her journey. She said, “When people hear they have cancer, it’s not unusual to feel devastated and terrified. I didn’t have that feeling. I had the feeling of ‘How lucky am I, that this was found?’”

Vicki stays active, teaching piano and working as a choral conductor. She said, “Nothing that I do has been negatively impacted by wearing the bag. Everything

that I do has been positively impacted.” One of the best parts of having an ileal conduit is at night I use a night bag, so I never have to get up to urinate in the middle of the night. It’s heaven.”

Vicki also believes that having a positive attitude can make a real difference. She told BCAN, “I want to go through it doing my best to live my fullest life. It doesn’t mean that I don’t honor scary feelings at times. But then it’s like, ‘Yeah, let’s get on with it.’ How do I choose to react to all of this?” 

New State-Specific Resources for Bladder Cancer Patients

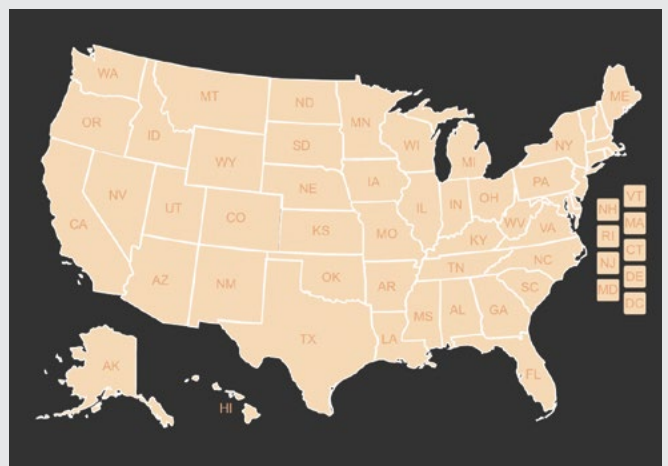
Although bladder cancer is a global disease, each patient feels the impact differently. Very few patients are in a position to travel to another state for treatment, so they seek out treatment in their home states. To help identify more locally-based resources, BCAN has developed a brand-new section of our bcan.org web site with state-specific bladder cancer information, including:

- The estimated number of individuals expected to be diagnosed with bladder cancer this year.
- NCI Designated Comprehensive Cancer Centers
- National Comprehensive Cancer Center Network member institutions
- Veterans Administration hospitals
- Bladder cancer clinical trials available in each state
- State health departments
- How to contact your state representatives

Simply visit bcan.org/bladder-cancer-by-state and click on your state. There, you’ll find a wealth of information and useful resources for your bladder cancer journey.



Statistics about bladder cancer cases in California and nationally



You can click on your state to find helpful resources

Bladder Cancer Events and Programs in 2022

BCAN has a host of exciting and informational activities happening in 2022 and we invite you to be part of them. Please visit our web site, bcan.org, to learn more.



APRIL—MAY

Walks to End Bladder Cancer

In-person and virtual Walks to End Bladder Cancer. Visit bcanwalk.org to find a Walk near you or join us virtually on May 7, 2022.



APRIL—MAY

Beacon of Hope Award

In April and May 2022, BCAN community members will nominate and choose that special person who has been a beacon of light in their bladder cancer journey.



MAY

Ask the Experts 2021

Our popular Q&A with leading bladder cancer doctors is back this year and will take place on May 25, 2022. Register at bcan.org/ask



OCTOBER

Summit for Patients and Families

The Bladder Cancer Summit for Patients and Families will take place in October of 2022.



ALL YEAR

Patient Insight Webinars

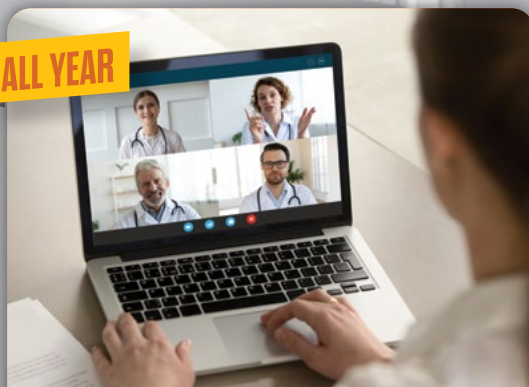
BCAN's popular webinar series brings information to your computer, tablet or smartphone. Please visit bcan.org/webinars.



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.



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.

Lionel's Story: A Great Life with a Neobladder, 25 Years Later

Lionel Cohen is a 25-year bladder cancer survivor and credits his longevity to his decision to opt for a neobladder more than two decades ago, and to the skill and expertise of Dr. Gary Steinberg, his surgeon. Lionel was diagnosed with non-muscle invasive bladder cancer in 1997 at the age of 65. He is now 89 years young and full of life. BCAN recently caught up with Lionel and his wife, Anne.

Lionel told us that, like many bladder cancer patients, he had the all-too-common symptom of blood in his urine – and occasionally, he would pass blood clots when urinating. Lionel recognized that “something was not right,” saw a urologist, and soon after had a cystoscopy. Unfortunately, it found that he had bladder cancer.

Lionel's wife Anne, who accompanied him throughout, said that during the procedure, the urologist called her into the room. Anne said, “They showed me that inside the bladder was this thing that looked like a rose. It was beautiful, but it was cancer.”

Wanting to help her husband, Anne then contacted a doctor friend who gave her a grim prognosis based upon what Anne related. Rallying her family, who wanted to help in any way they could, Anne remembered that one of her children had a connection to the University of Chicago. That's where they discovered Dr. Gary Steinberg. Dr. Steinberg spent many years as Chair of the BCAN's Scientific Advisory Board.

Anne told BCAN, “We went to see him and he explained everything. He was an absolute jewel in the sense that he took the time to call me and talk with me.”

Even nearly a quarter century later, Dr. Steinberg remembers Lionel. He told BCAN, “I remember Lionel and I know that he is a very friendly, warm person and had a lot of friends in his business career. I think he was very knowledgeable and put his faith into my hands many times.”

Lionel recalled that Dr. Steinberg took the time to explain to him exactly what type of surgery he was facing. Lionel recalls that Dr. Steinberg would also draw him pictures to help him understand.

Dr. Steinberg began doing radical cystectomies with neobladder creation in the fall of 1994 but for Lionel, the procedure was brand new. Now, years later, he describes living with a neobladder as completely normal.

He told BCAN, “I go to the restroom about every four hours, but besides that, this has been a beautiful story for me.” He added, “You may have to worry about dripping, but that depends on your fluid intake.”

Like some bladder cancer survivors, Lionel told BCAN that he began using a catheter in 2012. “I know some people get scared when they hear that word, but it is honestly not that bad. You are good to go as long as you have the right gel and gloves. Make sure you carry it with you. I have mine with me when I travel.”

In addition to being Lionel's surgeon, Dr. Steinberg also introduced him to the Bladder Cancer Advocacy Network . Lionel recalls attending a Walk to End Bladder Cancer in Chicago and seeing Dr. Steinberg there.

Now, years beyond his diagnosis and surgery, Lionel is introspective about his bladder cancer journey. He told BCAN, “When you hear the word cancer, the normal reaction is, ‘I'm dead.’ And that is not the case. Many more people survive this disease than did when I had my surgery.”

He added that anyone who experiences any of the signs and symptoms of bladder cancer like blood in the urine should “get off their butt and get to the doctor as soon as possible.”

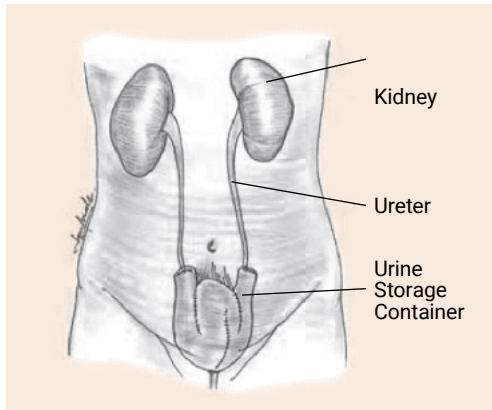
Lionel also noted, “I am excited to share my long-term success story with the bladder cancer community. There IS life after bladder cancer.”



Lionel and his wife, Anne.

► What is *Neobladder*?

A *neobladder* is a type of internal *urinary diversion* available following a *radical cystectomy*. If you have a radical cystectomy, the neobladder allows you to store urine in your body. You continue to pass urine through your *urethra*.



Neobladder means "new bladder". Your doctor will make a new bladder in the same place from a piece of the small intestine, called an *ileum*

► How is a Neobladder created?

Normally, urine passes from the kidneys through the *ureters* and into the bladder. From the bladder, urine moves through the *urethra* and out of the body. After removing the bladder, a segment of the small intestine is used to form a new (neo) *pouch* for urine.

This neobladder is attached to the ureters and the urethra, so urine passes through it like a normal bladder. By tensing the abdominal muscles and relaxing certain muscles, the patient can push the urine through the urethra. Some patients will be able to hold urine in their neobladder, but they may need to use a catheter to help remove the urine from their body.

Other patients are not able to have a neobladder because of the extent of their bladder tumor, decreased renal (kidney) function, their general health, or because of other treatments they have had in the past.



ASK YOUR HEALTHCARE TEAM

» *Is a neobladder a good urinary diversion option for me?*

- *What are the benefits and risks of the neobladder?*
- *What will happen if you decide you can not do a neobladder during the surgery?*

» *What will life be like with a neobladder?*

- *How much incontinence can I expect?*
- *What should I expect during recovery?*
- *What symptoms or side effects should I look out for after the surgery?*
- *How can I tell if I have a urinary tract infection?*

» *What is your experience with neobladder urinary diversions?*

*Always consider
a 2nd Opinion*



TERMS TO KNOW

- **Catheter:** A tube placed in the urethra to drain and collect urine from the bladder.
- **Chemotherapy:** The treatment of cancer disease by the use of chemical substances.
- **Incontinence:** Unable to restrain natural discharges of urine.
- **Neobladder:** A new bladder is constructed out of a piece of intestine and attached to the urethra. This is placed in the position that had been occupied by the bladder before it was removed because of disease.
- **Pouch:** A reservoir.
- **Radical cystectomy :** Removal of the bladder.
- **Ureter :** The tube that carries urine from the kidney to the bladder.
- **Urethra:** The tube through which urine leaves the body.
- **Urinary diversion:** A new way for urine to go from the kidneys out of the body created using a part of the intestine.
- **Urologist:** A doctor who specializes in diseases of the urinary organs in females and the urinary and sex organs of males.

WHAT YOU SHOULD KNOW: Advice from bladder cancer patients who are living with a neobladder

BEFORE YOUR NEOBLADDER SURGERY



Ask your doctor about any special preparations you should follow before your surgery. These can include:

- Any medication or herbal use you should avoid or stop taking
- Food and drink limitations

AFTER YOUR NEOBLADDER SURGERY



You can live a healthy, active life with a neobladder.

» *Getting used to the neobladder will take time and patience.*

- Emptying your new bladder will not work in the same way as a normal bladder. You must train your muscles to put pressure on the neobladder to force urine out. You will be shown how to perform pelvic floor exercises to strengthen those muscles.
- If you cannot urinate after the surgery, you might need to use a **catheter** to empty your bladder.
- The new bladder will start out small. As it is used, it will expand to hold more urine.

» *With care, you can avoid a lot of problems.*

- You will not be able to tell when your neobladder is full right away. Until you know the signs your bladder is full, set a regular schedule. Empty your new bladder regularly and completely, even at night.
- Be prepared for incontinence at first, especially at night. Use pads to protect your mattress. Adult diapers and pads can help during the day and at night. Set an alarm to wake up once or twice.
- Because your neobladder can absorb chemicals your kidneys have filtered out of your blood stream, it is important to empty your neobladder every 3-4 hours day and night. You should also empty your new bladder before it gets too full and may leak.
- Drink plenty of water during the day to keep the neobladder “flushed.” The neobladder produces mucous since it used to be a piece of intestine. That mucous can build up if it is not flushed away regularly. When well hydrated, your urine is pale yellow.
- A urinary tract infection (UTI) can occur. Watch for stronger smelling, cloudy, darker urine or blood in your urine. A UTI may also cause lower back pain. Contact your **urologist** if you suspect you have a UTI.

SUPPORT IS IMPORTANT

- Talk to your family and friends about your neobladder, and do not hesitate to ask for help.
- There are people who can help you with incontinence issues. For instance, a physical therapist can teach you pelvic floor exercises to strengthen your muscles.

NEXT STEPS:

- You will need occasional blood tests to check your body salts and kidney function.
- You will also need occasional imaging to confirm cancer has not recurred.
- You will still need regular checkups to make sure the cancer has not spread.
- Your doctor may recommend **chemotherapy** to help prevent the cancer from spreading.
- It can be helpful to talk to someone who has experience with a neobladder. Call the BCAN Survivor 2 Survivor program to connect with a volunteer who knows about having a neobladder. Dial 888-901-BCAN.

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Krisztina Walks for Bladder Cancer Patients

Krisztina Emodi is a nurse practitioner at the University of California San Francisco (UCSF). She works very closely with Dr. Sima Porten, a urologic cancer surgeon, a researcher at UCSF and a 2022 Walk to End Bladder Cancer ambassador.

Krisztina and Dr. Porten have been involved in the Walks for several years and Krisztina is now the captain of the university team, UCSF Bladder Heroes. She and her teammates will be participating in the Virtual Walk on May 7, 2022 and will walk to raise awareness about bladder cancer as well as critical funds for BCAN's free programs and services.

Krisztina's role is preoperative preparation for those patients who are about to have their bladder removed. The Walk to End Bladder Cancer is important to her because she has seen the value of the free information and programming that BCAN offers for patients. She and Dr. Porten frequently encourage bladder cancer patients to visit BCAN's web site to learn more about what to expect along their journeys with the disease.

Krisztina also offers a healthcare provider perspective on why BCAN's work is important to the bladder cancer community. She has attended the Bladder Cancer Think Tank, an annual gathering of bladder cancer physicians, researchers, advocates and other medical professionals and told BCAN "I attended the 2019 Bladder Cancer Think Tank and I can say with 100% certainty that it was one of the best meetings of my life." Krisztina noted the spirit of collaboration involving so many disciplines related to improving the lives of bladder cancer patients. "At Think Tank, I saw oncologists, pharmacists, nurses, epidemiologists, researchers, social workers and patients all working together to find solutions. It was such an amazing meeting."

We encourage you and your loved ones, colleagues and friends to sign up for the 2022 Walk to End Bladder Cancer. To join Krisztina's Virtual Walk team simply visit bcanwalk.org, click on "search teams" and look for "UCSF Bladder Heroes." You can also form your own team, or participate virtually or in one of the 14 in-person Walk cities across America. 

Join Krisztina Emodi June 7, 2022 for a webinar, "Urinary Tract Infections After a Radical Cystectomy." Sign up at: tinyurl.com/BCANregister



Nurse practitioner Krisztina Emodi, FNP, MPH, CNS



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

Webinars Deliver Crucial Bladder Cancer Information to You

This Spring, BCAN offers an abundance of free bladder cancer webinars featuring doctors, researchers, patients and more. You can conveniently view them from your computer, tablet or smartphone.

To register for any of these free webinars, please visit bcan.org/webinars. We are often adding new programming, so feel free to check back often.

Upcoming webinars:

Treatment Talk | What you need to know about treating upper tract urothelial carcinoma

March 1, 2022 at 5:00 PM ET

How to be a Proactive Patient

March 22, 2022 at 6:00 PM ET

CIS in Bladder Cancer – What does this diagnosis mean?

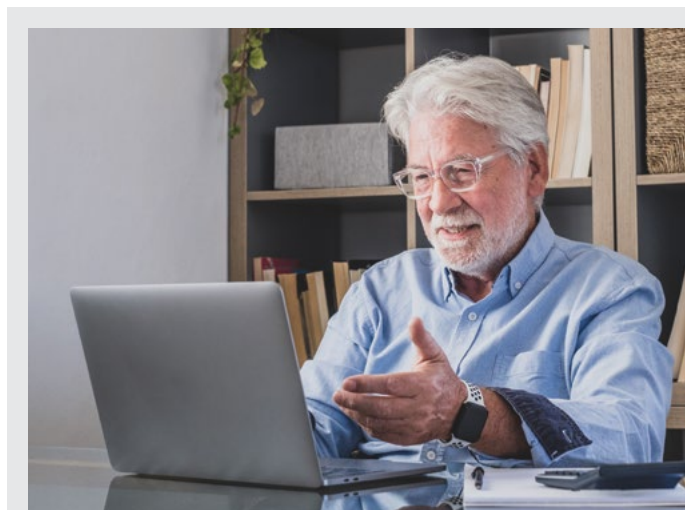
March 29, 2022 at 7:00 PM ET

Understanding Upper Tract Urothelial Carcinoma (UTUC)

April 5, 2022 at 5:00 PM ET

Treatment Talk | What you need to know about transurethral resection of bladder tumor (TURBT)

April 12, 2022 at 7:00 PM ET



In addition to the live programs, webinars are available on bcan.org and available to view 24/7.

The Care and Keeping of an Indiana Pouch

May 18, 2022 at 7:00 PM ET

Bladder Cancer Staging and Standards of Care | How is bladder cancer treated in 2022?

June 1, 2022 at 05:00 PM ET

Urinary Tract Infection After Radical Cystectomy

June 7, 2022 at 6:00 PM ET 

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



Join Us for Bladder Cancer Awareness Month


The 2022 Bladder Cancer Awareness Month in May promises to be the biggest and best ever. Annually during the month of May, thousands of people in the bladder cancer community work to raise awareness of what is the sixth-most commonly diagnosed cancer in America. Increasing public awareness can help people get into treatment for bladder cancer earlier and dramatically enhance their chances of survival.

Simply put, increased awareness can save lives.

At BCAN, during Bladder Cancer Awareness Month, we step up our efforts to bring attention to the disease, its warning signs and symptoms, as well as focusing on the critical need to invest more money in

medical research to help improve the lives of bladder cancer patients and those who love them.

May is also a celebration of bladder cancer survivors. According to the National Cancer Institute, there are more than 720,000 people living with bladder cancer in the United States – that’s more than the population of Vermont or Wyoming. We celebrate the heroic patients who have survived this terrible disease.

As we draw closer to May, BCAN will publish a downloadable social media toolkit containing information on our web site including facts and figures and graphics that you can share across your Facebook, Twitter, or Instagram accounts. 


Bladder Cancer Matters Podcast

Now in its second season, BCAN’s podcast is by, for and about members of the bladder cancer community.

Available episodes include:

- **What’s Up with Bladder Cancer and BCG** with Dr. Ashish Kamat
- **What You Need to Know About COVID Vaccines and Bladder Cancer** with Dr. Seth Lerner and Dr. Laila Woc-Colburn
- **Personalized Medicine for Bladder Cancer Patients** with Dr. Matthew Milowsky
- **The Pluses and Minuses of Cystoscopies, TURBTs and Other Diagnostic Tools** with Dr. Alexander Kutikov
- **Battling Aggressive Bladder Cancer in the Era of COVID – Margo’s Story**
- **What You Need to Know About Smoking and Bladder Cancer** with Dr. Richard Matulewicz
- **How Patients Can Navigate the BCG Shortage** with Dr. Robert Svatek

You can listen to these podcast episodes on BCAN’s web site at bcan.org/podcasts.

Never miss an episode by subscribing on your favorite podcasting platform by searching for “Bladder Cancer Matters” and clicking the “subscribe” button. 

**BLADDER
CANCER
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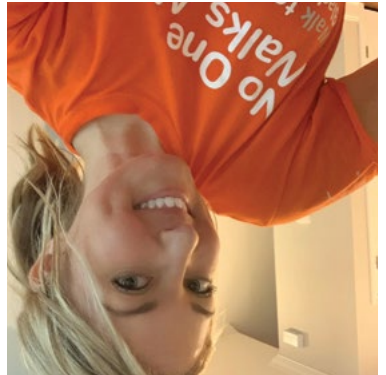


Leading the way to awareness and a cure

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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 or text WALK to 1-888-901-BCAN (2226).

