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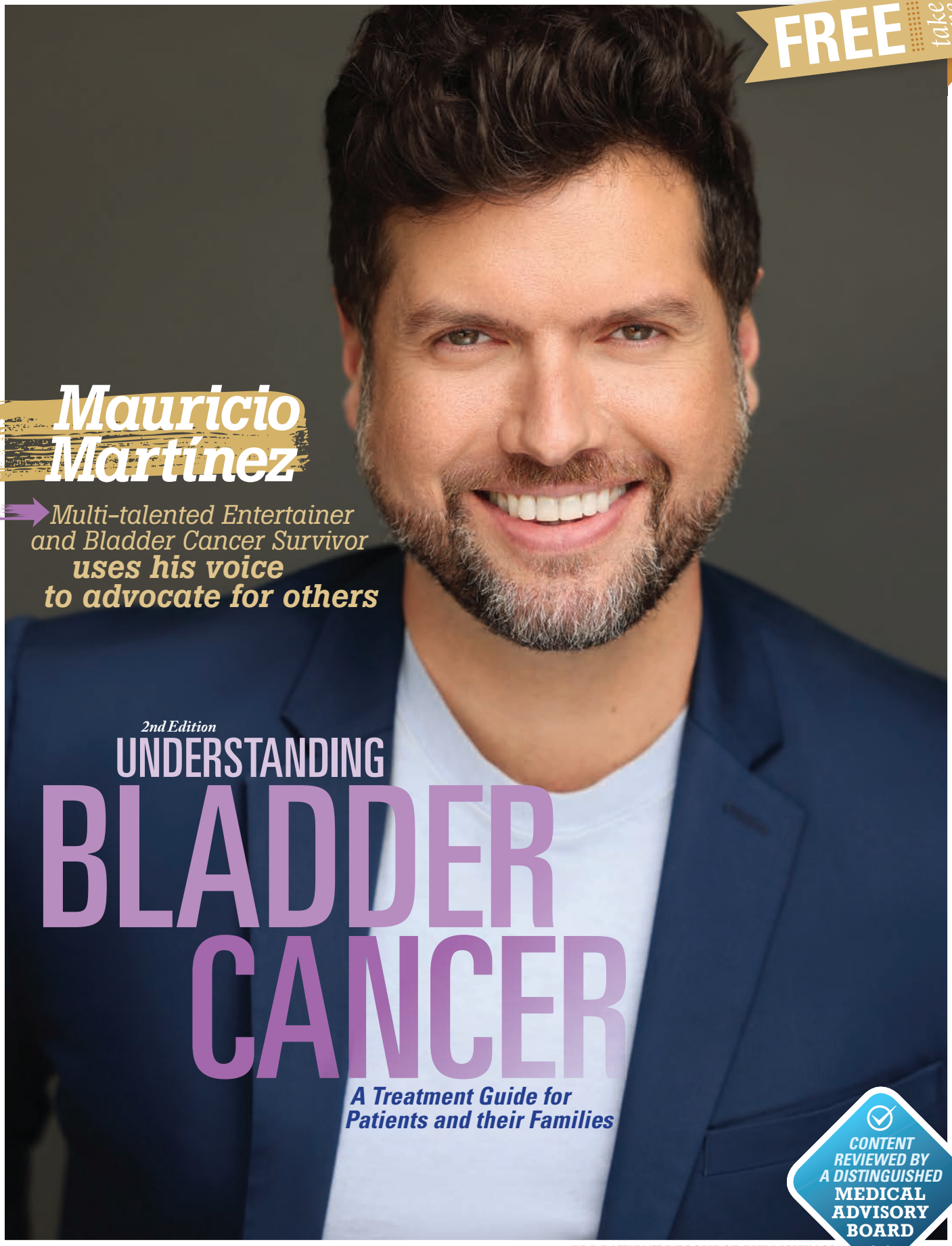

Mauricio Martínez

Multi-talented Entertainer and Bladder Cancer Survivor **uses his voice to advocate for others**

2nd Edition

UNDERSTANDING BLADDER CANCER

A Treatment Guide for Patients and their Families

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD

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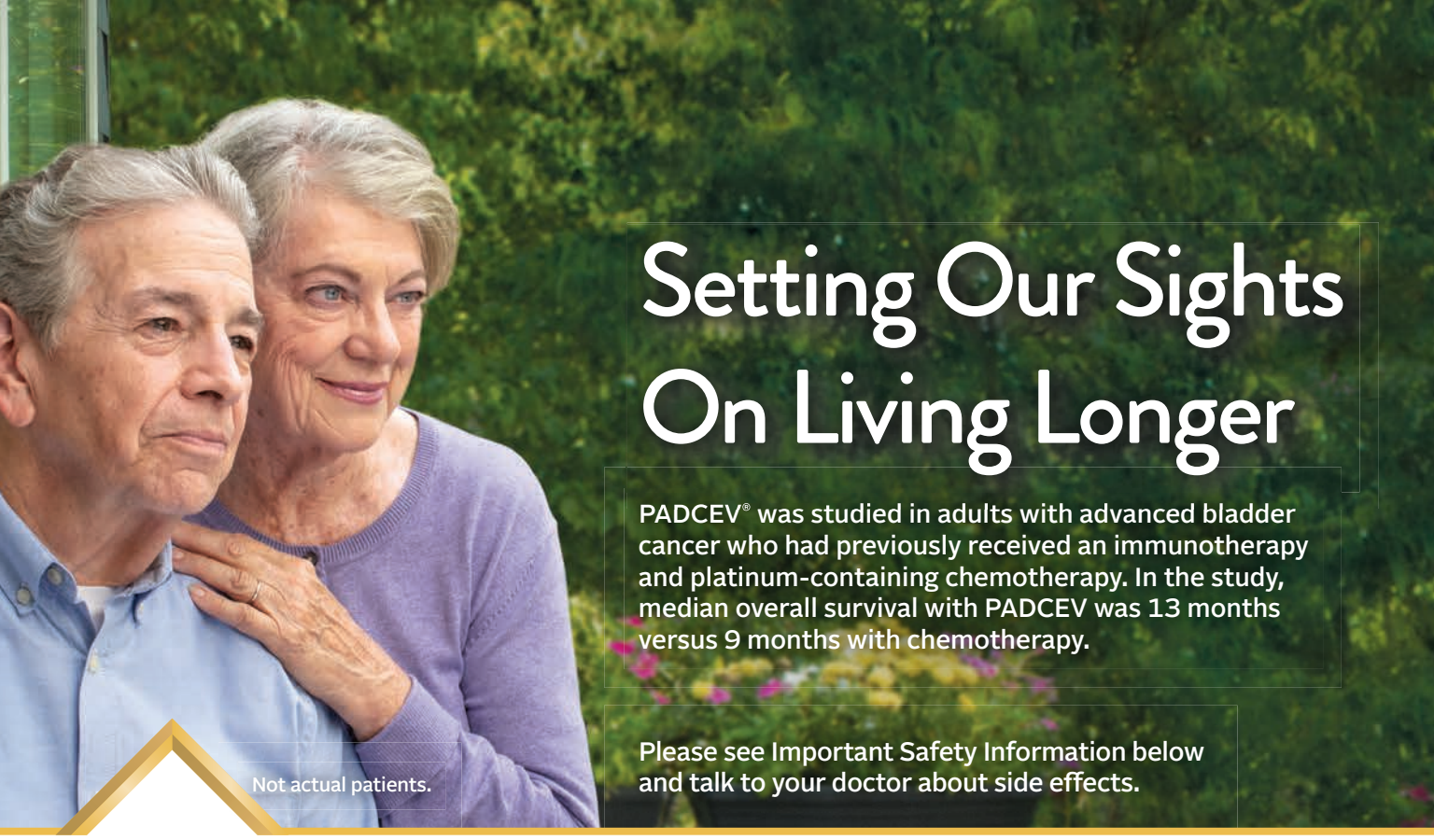

Setting Our Sights On Living Longer

PADCEV® was studied in adults with advanced bladder cancer who had previously received an immunotherapy and platinum-containing chemotherapy. In the study, median overall survival with PADCEV was 13 months versus 9 months with chemotherapy.

Please see Important Safety Information below and talk to your doctor about side effects.

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about PADCEV?

PADCEV may cause serious side effects, including:

Skin reactions. Severe skin reactions have happened in people treated with PADCEV; in some cases severe skin reactions have caused death. Most severe skin reactions occurred during the first cycle (28 days) of treatment but may happen later. Your healthcare provider will monitor you during treatment and may prescribe medicines if you get skin reactions. Tell your healthcare provider right away if you develop any of these signs of a new or worsening skin reaction:

- target lesions (skin reactions that look like rings)
- rash or itching that continues to get worse
- blistering or peeling of the skin
- painful sores or ulcers in mouth or nose, throat, or genital area
- fever or flu-like symptoms
- swollen lymph nodes

See **"What are the possible side effects of PADCEV?"** for more information about side effects.

WHAT IS PADCEV?

PADCEV is a prescription medicine used to treat adults with bladder cancer and cancers of the urinary tract (renal pelvis, ureter or urethra) that has spread or cannot be removed by surgery. PADCEV may be used if you:

- have received an immunotherapy medicine **and** chemotherapy that contains platinum, **or**
- you are not able to receive a chemotherapy that contains the medicine cisplatin and you have received one or more prior therapy.

It is not known if PADCEV is safe and effective in children.

Before receiving PADCEV, tell your healthcare provider about all of your medical conditions, including if you:

- are currently experiencing numbness or tingling in your hands or feet
- have a history of high blood sugar or diabetes
- have liver problems
- are pregnant or plan to become pregnant. PADCEV can harm your unborn baby. Tell your healthcare provider right away if you become pregnant or think you may be pregnant during treatment with PADCEV
- are breastfeeding or plan to breastfeed. It is not known if PADCEV passes into your breast milk. Do not breastfeed during treatment and for at least 3 weeks after the last dose of PADCEV

Females who are able to become pregnant:

- Your healthcare provider should do a pregnancy test before you start treatment with PADCEV.
- You should use an effective method of birth control during your treatment and for at least 2 months after the last dose of PADCEV.

Males with a female sexual partner who is able to become pregnant:

- If your female partner is pregnant, PADCEV can harm the unborn baby.
- You should use an effective method of birth control during your treatment and for at least 4 months after the last dose of PADCEV.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking PADCEV with certain other medicines may cause side effects.

How will I receive PADCEV?

- PADCEV will be given to you by intravenous (IV) infusion into your vein over 30 minutes.
- You will receive your PADCEV over periods of time called cycles.
  - Each PADCEV cycle is 28 days.
  - You will receive PADCEV on days 1, 8 and 15 of every cycle.
- Your healthcare provider will decide how many treatment cycles you need.
- Your healthcare provider may do blood tests regularly during treatment with PADCEV.

What are the possible side effects of PADCEV?

PADCEV may cause serious side effects, including:

- **Skin Reactions.** See **"Skin Reactions"** above for more information.

PADCEV is approved to treat your **advanced bladder cancer*** if you have received:

Immunotherapy and platinum-containing chemotherapy

OR

Prior therapy and could not receive cisplatin chemotherapy

Ask your healthcare professional if PADCEV is right for you or your loved one

Visit PADCEV.com or call 1-888-4PADCEV (1-888-472-3238) for more information

*Bladder cancer and cancers of the urinary tract (renal pelvis, ureter or urethra) that has spread or cannot be removed by surgery.

- **High Blood Sugar (hyperglycemia).** You can develop high blood sugar during treatment with PADCEV. High blood sugar, a serious condition called diabetic ketoacidosis (DKA), and death have happened in people with and without diabetes who were treated with PADCEV. Tell your healthcare provider right away if you have any symptoms of high blood sugar, including: frequent urination, increased thirst, blurred vision, confusion, it becomes harder to control your blood sugar, drowsiness, loss of appetite, fruity smell on your breath, nausea, vomiting, or stomach pain.
- **Lung problems.** PADCEV may cause severe or life-threatening inflammation of the lungs that can lead to death. Tell your healthcare provider right away if you get new or worsening symptoms, including trouble breathing, shortness of breath, or cough.
- **Peripheral neuropathy.** You may develop nerve problems called peripheral neuropathy during treatment with PADCEV. Tell your healthcare provider right away if you get new or worsening numbness or tingling in your hands or feet, or muscle weakness.
- **Eye problems.** You can develop certain eye problems during treatment with PADCEV. Tell your healthcare provider right away if you have dry eyes, blurred vision, or any vision changes. You may use artificial tear substitutes to help prevent or treat dry eyes.
- **Leakage of PADCEV out of your vein into the tissues around your infusion site (extravasation).** If PADCEV leaks from the injection site or the vein into the nearby skin and tissues, it could cause an infusion site reaction. These reactions can happen right after you receive an infusion, but sometimes may happen days after your infusion. Tell your healthcare provider or get medical help right away if you notice any redness, swelling, itching, or discomfort at the infusion site.

The most common side effects of PADCEV include:

- skin rash
- changes in liver and kidney function tests
- increased sugar (glucose) in the blood
- tiredness
- numbness or tingling in your hands or feet, or muscle weakness
- decreased white blood cell, red blood cell, and platelet counts
- hair loss
- decreased appetite
- diarrhea
- decreased sodium, phosphate and protein (albumin) in the blood
- nausea
- itching
- change in sense of taste
- increased uric acid in the blood
- increased lipase (a blood test done to check your pancreas)
- decreased weight
- dry skin

If you have certain side effects, your healthcare provider may decrease your dose or stop your treatment with PADCEV for a period of time (temporarily) or completely.

PADCEV may cause fertility problems in males, which may affect the ability to father children. Talk to your healthcare provider if you have concerns about fertility.

These are not all the possible side effects of PADCEV.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

Please see Brief Summary of full Prescribing Information (Prescription Drug Facts), with an Important Warning of Serious Side Effects on adjacent page.

astellas Seagen

PADCEV®
enfortumab vedotin-ejfv
Injection for IV infusion 20 mg & 30 mg vials

Prescription Drug Facts — *Rx Only*

Active Ingredient	*Purpose*
PADCEV (enfortumab vedotin-ejfv) injection for IV infusion 20mg or 30mg vials	Cancer Treatment

Important Warning Severe skin reactions have happened in people treated with PADCEV, in some cases severe skin reactions have caused death. Most severe skin reactions occurred during the first cycle (28 days) of treatment but may happen later. Your healthcare provider will monitor you during treatment and may prescribe medicines if you get skin reactions. Tell your healthcare provider right away if you develop any of these signs of a new or worsening skin reaction: ■ target lesions (skin reactions that look like rings) ■ rash or itching that continues to get worse ■ blistering or peeling of the skin ■ painful sores or ulcers in mouth or nose, throat, or genital area ■ fever or flu-like symptoms ■ swollen lymph nodes
See ***"Warnings"*** below for more information about serious side effects of PADCEV.

Uses Treatment of adults with bladder cancer and cancers of the urinary tract (renal pelvis, ureter, or urethra) that has spread or cannot be removed by surgery. PADCEV may be used if you:
■ have received an immunotherapy medicine **and** chemotherapy that contains platinum, **or**
■ you are not able to receive a chemotherapy that contains the medicine cisplatin and you have received one or more prior therapy.
It is not known if PADCEV is safe and effective in children.

Warnings

Ask a doctor before use if you have
■ numbness or tingling in your hands/feet ■ have a history of high blood sugar or diabetes ■ have liver problems

What are the possible serious side effects of PADCEV?
■ skin reactions. See ***"Important Warning"*** above ■ high blood sugar (hyperglycemia), including diabetic ketoacidosis (DKA), sometimes resulting in death ■ lung problems ■ nerve problems (peripheral neuropathy) like tingling in your hands or feet or muscle weakness ■ eye problems ■ infusion site reactions if PADCEV leaks out of your veins into tissues around your infusion site (extravasation)

Tell your doctor if you have
■ target lesions (skin reactions that look like rings), rash/itching that continues to get worse, skin blistering or peeling, painful sores in the mouth, nose, throat, or genital area, fever/flu-like symptoms, or swollen lymph nodes ■ frequent urination, increased thirst, blurred vision, confusion, it becomes harder to control your blood sugar, drowsiness, loss of appetite, fruity smell on your breath, nausea, vomiting, or stomach pain ■ trouble breathing, shortness of breath, or cough ■ numbness or tingling in your hands or feet or muscle weakness ■ dry eyes, blurred vision, or any vision changes ■ redness, swelling, itching, or discomfort at the infusion site, or get medical help right away.

If pregnant, able to become pregnant, or have a partner who is able to become pregnant
■ PADCEV can harm your unborn baby, talk to your doctor ■ females should use effective birth control during treatment and for at least 2 months after the last dose of PADCEV ■ males should use effective birth control during treatment and for at least 4 months after the last dose of PADCEV

If breastfeeding
■ do not breastfeed during treatment and for at least 3 weeks after the last dose of PADCEV

Fertility
■ PADCEV may cause fertility problems in males, which may affect the ability to father children

PADCEV®
enfortumab vedotin-ejfv
Injection for IV infusion 20 mg & 30 mg vials

081-0571-PM 07/21

Prescription Drug Facts Continued

Most Common Side Effects

■Skin rash ■changes in liver and kidney function tests ■increased sugar (glucose) in the blood ■tiredness ■numbness or tingling in your hands or feet, or muscle weakness ■decreased white blood cell, red blood cell, and platelet counts ■hair loss ■decreased appetite ■diarrhea ■decreased sodium, phosphate, and protein (albumin) in the blood ■nausea ■itching ■change in sense of taste ■increased uric acid in the blood ■increased lipase (a blood test done to check your pancreas) ■decreased weight ■dry skin

If you have certain side effects, your healthcare provider may decrease your dose or stop your treatment with PADCEV for a period of time (temporarily) or completely.

These are not all of the possible side effects of PADCEV. **You may report side effects to FDA at 1-800-FDA-1088** or **www.fda.gov/medwatch**.

Directions

■PADCEV will be given by intravenous (IV) infusion over 30 minutes ■you will receive PADCEV over periods of time called cycles ■each cycle is 28 days and PADCEV will be given on days 1, 8, and 15 of every cycle ■your doctor will decide how many treatment cycles you need ■your doctor may do blood tests regularly during your treatment

Other Information Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking PADCEV with certain other medicines may cause side effects.

If you would like more information about PADCEV, talk with your healthcare provider. You can ask your pharmacist or healthcare provider for information about PADCEV that is written for healthcare professionals (full Prescribing Information) which includes more information about the ***Important Warning*** with PADCEV.

Inactive Ingredients histidine, histidine hydrochloride monohydrate, polysorbate 20, and trehalose dehydrate.

PADCEV®
enfortumab vedotin-ejfv
Injection for IV infusion 20 mg & 30 mg vials

081-0571-PM 07/21

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IN THIS GUIDE

"The mental health aspect of a cancer diagnosis can be hard to handle — especially because having cancer can be isolating."

Mauricio Martínez, *page 7*

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Office Address	**8455 Lenexa Drive** **Overland Park, KS 66214**
For Additional Information	**prp@patientresource.com**
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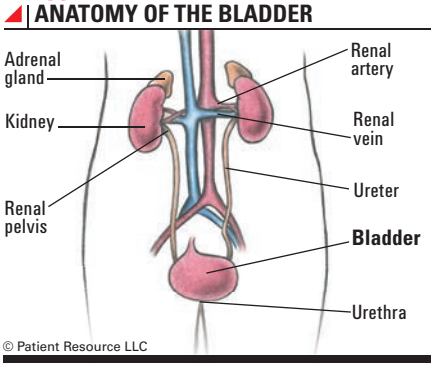
Understanding your diagnosis leads to empowerment

When you first hear you have bladder cancer, you may feel overwhelmed. Everything may seem unfamiliar and confusing, making you feel disconnected. Know that you will be surrounded by a multidisciplinary team of skilled health care professionals who are prepared to support and guide you. They will help you see that you are more than your cancer diagnosis.

One of the first things you can do is to learn as much as possible about the type of bladder cancer you have and its treatments. This guide will provide you with information about the types of bladder cancer, staging, treatments, support services and more.

FIGURE 1

ANATOMY OF THE BLADDER



Becoming an informed patient will help empower you to make the decisions ahead. If there is something you do not understand, ask your doctor to explain.

BLADDER CANCER BASICS

The bladder is a hollow, expandable muscular organ that collects and stores urine produced in the kidneys (see Figure 1). Urine flows from the kidneys to the bladder through two thin tubes called ureters. The urinary tract, which includes the renal pelvis, ureters, bladder and urethra, is lined with urothelial cells that can change shape and stretch without breaking apart.

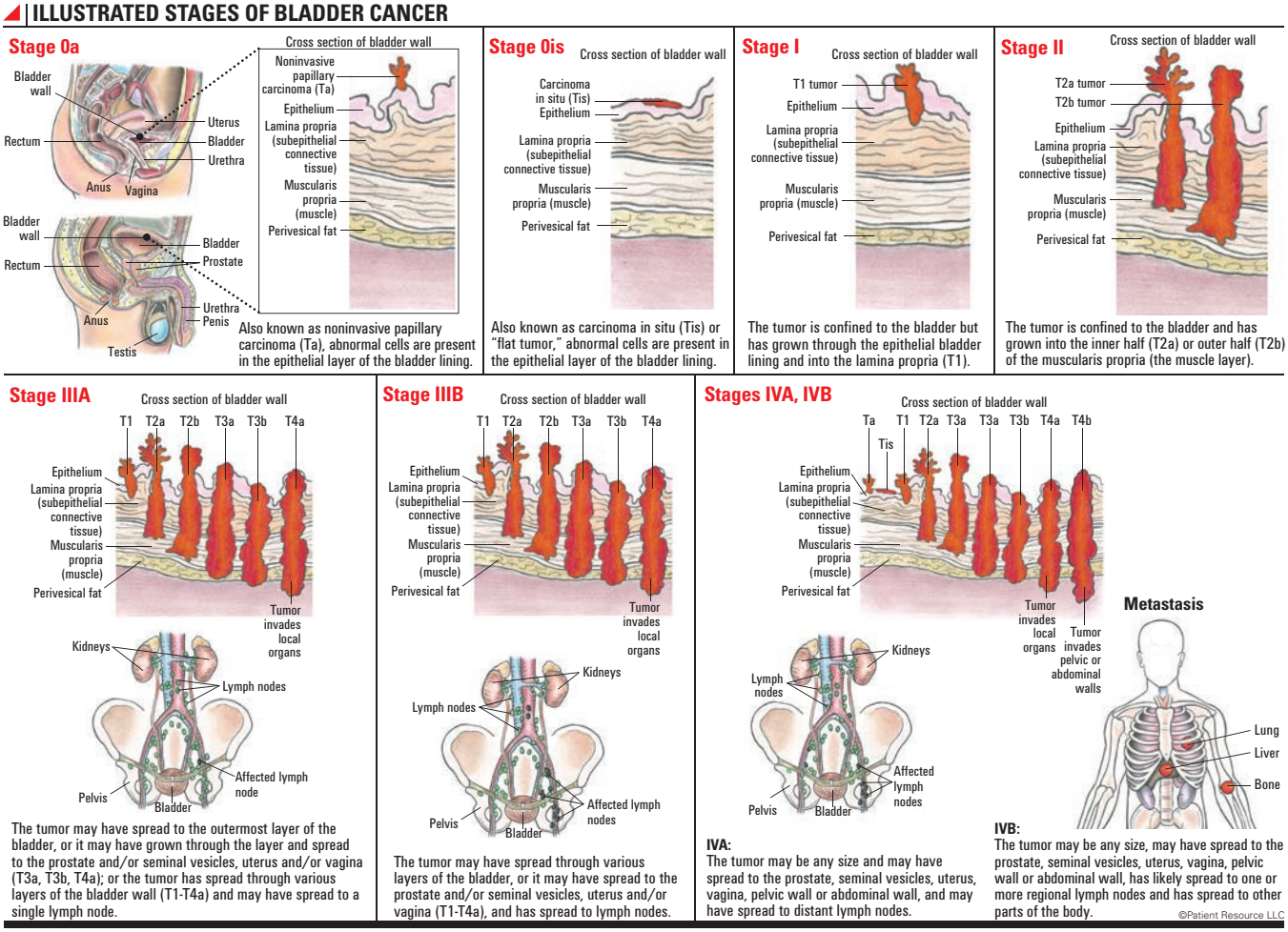
The bladder wall is flexible, and the bladder can hold approximately two cups of urine. When it is full and you are ready to urinate, the muscles in the bladder wall contract and force the urine out of the body through a tube called the urethra. The bladder wall is composed of four layers:

- Urothelium: Also called the transitional epithelium or mucosa, this innermost layer is composed of cells called urothelial or transitional cells.
- Lamina propria: The next layer is composed of thin connective tissue, blood vessels and nerves.
- Muscularis propria: Thick muscle makes up the third layer. Together with the lamina propria, it is also called the submucosa.
- Serosa: The outermost layer is made up of fatty connective tissue (known as perivesical fat) to help separate the bladder from nearby organs and protect it.

Bladder cancer develops when genes in normal cells mutate and cause the cells to multiply uncontrollably. They form a disorganized mass of billions of abnormal cells called a tumor.

The most common type of bladder cancer

ILLUSTRATED STAGES OF BLADDER CANCER



is urothelial carcinoma, also called transitional cell carcinoma. Other forms (called histologic subtypes) of bladder cancer include squamous cell carcinoma, adenocarcinoma and small cell carcinoma, all of which are almost always invasive. Also important in describing a bladder cancer is its form or morphology. There are two subtypes: papillary and flat. Papillary tumors grow from the bladder's inner lining toward the center of the bladder, while flat tumors grow along the surface of the lining.

Bladder tumors are also described by their invasiveness:

- Noninvasive tumors have not penetrated any other layers of the bladder.
- Non-muscle invasive tumors have grown into the lamina propria but not into the muscle.
- Muscle-invasive tumors have grown into the bladder's wall muscle and sometimes into surrounding tissues or organs outside the bladder.

TABLE 1
AJCC TNM SYSTEM FOR CLASSIFYING BLADDER CANCER

Classification	Definition
Tumor (T)	
TX	Primary tumor cannot be assessed.
T0	No evidence of primary tumor.
Ta	Non-invasive papillary carcinoma (tumor with a "stalk").
Tis	Urothelial carcinoma in situ: "flat tumor" (or red, inflamed looking area).
T1	Tumor invades lamina propria (subepithelial connective tissue).
T2 T2a T2b	Tumor invades muscularis propria (muscle). Tumor invades superficial muscularis propria (inner half of muscle). Tumor invades deep muscularis propria (outer half of muscle).
T3 T3a T3b	Tumor invades perivesical soft tissue (fatty tissue that surrounds the bladder). Microscopically. Macroscopically (extravesical mass).
T4 T4a T4b	Extravesical tumor directly invades any of the following: prostatic stroma, seminal vesicles, uterus, vagina, pelvic wall, abdominal wall. Extravesical tumor invades directly into prostatic stroma, seminal vesicles, uterus, vagina. Extravesical tumor invades pelvic wall, abdominal wall.
Node (N)	
NX	Lymph nodes cannot be assessed.
N0	No lymph node metastasis.
N1	Single regional lymph node metastasis in the true pelvis (perivesical, obturator, internal and external iliac, or sacral lymph node).
N2	Multiple regional lymph node metastasis in the true pelvis (perivesical, obturator, internal and external iliac, or sacral lymph node metastasis).
N3	Lymph node metastasis to the common iliac lymph nodes.
Metastasis (M)	
M0	No distant metastasis.
M1 M1a M1b	Distant metastasis. Distant metastasis limited to lymph nodes beyond the common iliacs. Non-lymph-node distant metastases.

STAGING AND GRADING

Following your diagnosis, your doctor needs to determine the extent of the disease – a process called staging – to choose the best treatment option for you.

Bladder tumors, as with other cancers, are staged in two phases:

1. **Clinical stage** — based on the results of a physical examination, evaluation of biopsy specimens, and the results of imaging studies and CT scans.
2. **Pathologic stage** — based on more invasive testing, including surgery, to accurately establish how far the disease has spread. Assigning this stage normally includes the removal and testing of bladder tissue and/or nearby lymph nodes for examination. This stage is assigned by a pathologist, a specialist in determining the cause of diseases, including cancer.

Bladder cancer is classified according to the tumor, node and metastasis (TNM) system developed by the American Joint Committee on Cancer (AJCC). Doctors categorize the tumor (T) according to its depth of invasion, whether cancer cells are found in nearby lymph nodes (N), and whether it has metastasized (M), or spread, to other parts of the body. Once the cancer is classified, an overall stage is assigned (see Tables 1 and 2).

TABLE 2
STAGES OF BLADDER CANCER

Stage	T	N	M
0a	Ta	N0	M0
0is	Tis	N0	M0
I	T1	N0	M0
II	T2a,T2b	N0	M0
IIIA	T3a, T3b, T4a T1-T4a	N0 N1	M0 M0
IIIB	T1-T4a	N2, N3	M0
IVA	T4b Any T	Any N Any N	M0 M1a
IVB	Any T	Any N	M1b

TABLE 3
GRADES OF BLADDER CANCER

Classification	Definition
Urothelial Histologies	
LG	Low-grade.
HG	High-grade.
Squamous Cell Carcinoma and Adenocarcinoma	
GX	Grade cannot be assessed.
G1	Well differentiated.
G2	Moderately differentiated.
G3	Poorly differentiated.

Urothelial cancer is also described by grade (G), which is determined by how much the cancer cells look like healthy cells when viewed under a microscope (see Table 3). The grade may also indicate how likely the cancer is to recur, grow or spread. If cancer has spread beyond the bladder, your doctor may recommend biomarker testing to check for genetic mutations, which may guide treatment (see *Illustrated Stages of Bladder Cancer*, page 5).

TUMOR GENOMICS

Genomic testing is used to examine a cancer's genes to identify mutations that could indicate the cancer's behavior, how aggressive it might be and whether it will metastasize (spread). This information can lead to a more precise diagnosis and a more personalized treatment plan.

In bladder cancer, genomic testing is increasingly being used to determine whether the tumor has certain targetable characteristics that would indicate which type of treatment may be better suited. This testing is performed on a sample of tumor tissue.

If a mutation is found, your doctor will select a treatment that may target your cancer's specific mutation. But not all mutations have approved treatments available. If the testing does not identify a specialized treatment, standard of care and clinical trials will be the options to consider.

Mutations found in some bladder cancers include the *FGFR2* and *FGFR3* gene, *TP53, ATM/RB1* and *ERCC2* gene, among others. Ongoing research is looking for additional mutations that may affect the treatment or prognosis (outlook) of bladder cancer.

GETTING A SECOND OPINION

Seeking a second opinion is recommended for multiple reasons. Some doctors may favor one treatment approach, while others might suggest a different combination of treatments. Another doctor's opinion may change the diagnosis or reveal a treatment your first doctor was not aware of. You need to hear reasons and recommendations for all of your treatment options. A second opinion is also a way to make sure your pathology diagnosis and staging are accurate.

Other specialists can confirm your pathology report and stage of cancer and might suggest changes or alternatives to the proposed treatment plan. They can also answer any additional questions you may have. ■

Diagnosed for the first time at 31, Mexican-born actor and singer Mauricio Martínez has battled bladder cancer four times. He is the first to admit how mentally and emotionally challenging a cancer diagnosis can be, especially when it returns. He is dedicated to raising awareness about bladder cancer and the subsequent need for mental health services. Today, he is cancer-free and performing again.

Star of theater, music & television reaches out to others facing bladder cancer:

STAY ON YOUR FEET

Facing cancer multiple times has given me a new perspective on life, and I am passionate about sharing what I've learned. The mental health aspect of a cancer diagnosis can be hard to handle — especially because having cancer can be isolating, but it is just as important to treat as your physical self during treatment.

Going through cancer and its recurrences put me on an emotional rollercoaster. I had days where I would curse and scream in my apartment. Sometimes, I cried all day. Then there were days I was happy and so grateful for my blessings. By openly and honestly sharing my experiences, I hope to encourage others to reach out for help when needed.

By the time I was 40, I'd had bladder cancer four times. The first time I knew something was wrong was when my urine suddenly looked like red wine. I was 31 and living in Mexico. Alarmed, I called the doctor but it was the middle of spring break and Holy Week, so I had to wait three long days before I could get in with a urologist. Results of an X-ray and ultrasound showed five tumors in my bladder.

According to my doctor, developing bladder cancer at my age was not typical. He said it's often referred to as "an old man's disease." He took immediate action. The next day, I had a transurethral bladder tumor resection (TURBT) to burn off the tumors, including a partial cystectomy and surgery to remove several lymph nodes in my chest and pelvis area. Because it was diagnosed as Stage II bladder cancer and considered aggressive, we also treated it with intravesical chemotherapy and BCG followed by 27 radiation therapy sessions. I felt very lucky I was able to keep part of my bladder, but I was concerned and nervous about whether it would interfere with my singing and acting career. Fortunately, after I rested for two months and religiously kept my check-up appointments, I was able to return to work.

Three years later during a regular follow-up visit, the doctor found a tiny tumor in my bladder. I knew we had to treat it, but it took an emotional toll. I was shooting a movie in Mexico, so my doctor said we could wait to start treatment until after I finished because it was Stage I and was non-aggressive. When I finished the movie, we started intravesical chemotherapy, which was successful.

The next recurrence was three years later when I was shooting a TV show. This time, I felt less alarmed and more prepared to treat it. I had intravesical chemotherapy, and again, it was successful.

The most recent recurrence happened on the national tour of *On Your Feet*. At intermission, I saw my urine was once again that red wine color. Doctors found four new tumors, and they were aggressive.

This was heartbreaking because just four months prior, my scans were clean. It hit me hard emotionally. I had been fighting bladder cancer for nine years, but I was determined to beat it again. I had three to four months of intravesical chemotherapy and have been cancer-free ever since. Today, I'm living my life and performing again!

I feel fortunate that I was able to manage the physical side effects of treatment pretty well. Although I had body aches, weird body temperature changes and the need to wear catheters more than 40 times during various treatments, they didn't interfere with me staying in shape and performing. I often went to the gym right after a treatment. And, I didn't lose my hair because my therapy was intravesical instead of systemic, meaning it never went through my entire bloodstream. I am grateful I kept my hair because it helped me feel more comfortable while I was performing.

Being surrounded by friends and family, including my acting family, and a mental health counselor who showed me I needed to express all the emotions that came up helped a great deal. I gave myself permission to feel everything, so that I could move through it. I also read Gilda Radner's book about her experience with cancer, and it inspired me to write about my feelings, my cancer and the need to pay attention to my mental health.

I may have to fight bladder cancer for the rest of my life, but I've come to terms with it because I've learned that I am resilient. ■

Mauricio's Advice

1. **Only you can decide the correct path for you.**
2. **Know that you're not alone.**
3. **Research and join groups online. Talk to other survivors, both people in your culture and others, to broaden your view.**
4. **Ask for a second, third or fourth opinion. One doctor's approach may be completely different from another's. There are so many ways to fight cancer now.**
5. **Early detection is key.**
6. **Share your experience with others. Do not keep it to yourself.**
7. **Show cancer who's boss!**

More options to choose from when personalizing your plan

Recent advances in understanding and treating bladder cancer are bringing hope to many people affected by this disease. More treatments are now available and even more are expected in the future. Research in clinical trials is advancing quickly to find more effective therapies and better ways to provide the best care for managing side effects of the disease and its treatment.

Once you receive a diagnosis, you will work closely with your doctor to develop a treatment plan. It is an important time to discuss any concerns you have and your expectations for maintaining independence with certain physical activities of daily living, as treatment may change the way you urinate. Always ask questions and request explanations for anything you do not understand.

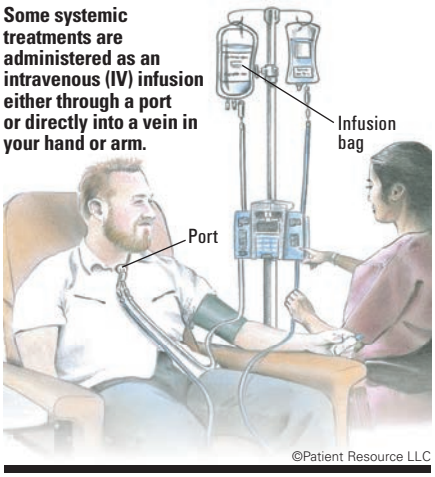
Your doctor will continually monitor your condition and make adjustments for a number of reasons. Keep in mind that cancer is an ever-changing condition that presents many challenges, so flexibility and patience are important.

TREATMENT OPTIONS

To develop a treatment plan tailored to you and the type of cancer you have, your doctor considers many factors, including the tumor's stage, grade and biomarker status; whether the cancer is non-muscle invasive or muscle-invasive; potential side effects; your general health; and your preferences concerning urine control. The following treatment options may be used alone or in combination.

Surgery is the primary method for treating a solid tumor. Removing it may offer the best chance of controlling the disease and keeping it from spreading, especially for people with early-stage disease.

FIGURE 1
SYSTEMIC THERAPY



Some systemic treatments are administered as an intravenous (IV) infusion either through a port or directly into a vein in your hand or arm.

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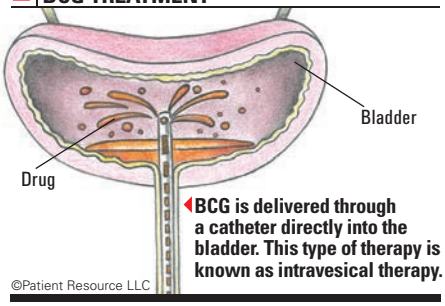
Your doctor may also perform a surgical procedure to stage the cancer or to relieve or prevent symptoms that occur later. Different procedures include the following:

- Transurethral bladder tumor resection (TURBT). A surgeon inserts a cystoscope through the urethra into the bladder and removes the tumor using an instrument with a small wire loop, a laser or high-energy electricity. TURBT may be used to diagnose, stage and treat bladder cancer.
- Cystectomy. A radical cystectomy removes the entire bladder and may also include nearby tissues or organs. Lymph nodes in the pelvis are also removed. In addition, men may have their prostate and urethra removed, and women may have their uterus, fallopian tubes, ovaries and part of the vagina removed. A partial (segmental) cystectomy may be performed to remove only a portion of the bladder, preserving the ability to urinate normally. In some cases, a cystectomy may be done laparoscopically or robotically.
- Urinary diversion. If your bladder is removed, a way to store and pass urine must be created. You and your treatment team will determine which of the three types of diversion will work best for you (see *Reconstruction*, page 10).
  - An ileal conduit involves creating a new tube from a piece of intestine (ileum) to allow your kidneys to drain and exit through a small opening called a stoma.
  - A continent cutaneous pouch is a pouch inside your body made from a segment of your intestine that is attached to your ureters, allowing urine to be stored internally and then removed through a hole in your abdomen.
  - A neobladder, also referred to as a substitute bladder, uses a portion of your intestine to connect the ureters and the other end to the urethra (tube through which urine exits the body).

Drug therapy may include chemotherapy, immunotherapy or targeted therapy. These therapies may be used alone or in combination with other therapies.

FIGURE 2
BCG TREATMENT



BCG is delivered through a catheter directly into the bladder. This type of therapy is known as intravesical therapy.

©Patient Resource LLC

Chemotherapy uses drugs to kill rapidly multiplying cells throughout the body. It is typically delivered in cycles, with treatment periods followed by rest periods to give your body time to recover. A specific strategy may consist of a single chemotherapy drug, a combination given at the same time or drugs given one after another. Chemotherapy may be used alone or with other forms of treatment. It may be used before surgery (neoadjuvant) or after surgery (adjuvant).

In bladder cancer, chemotherapy may be given intravesically or systemically.

- Intravesical (local) chemotherapy delivers drugs into the bladder through a catheter inserted through the urethra. Local treatment only destroys superficial tumor cells that come in contact with the chemotherapy solution. It cannot reach tumor cells that have invaded the muscular layer of the bladder wall or tumor cells that have spread to other organs.
- Systemic chemotherapy is given intravenously (IV) through a small tube inserted into a vein or port (see Figure 1). It travels through the bloodstream.

Immunotherapy harnesses the potential of the body's own immune system to recognize and destroy cancer cells. Several types of immunotherapy are approved for bladder cancer, including cytokines, immune checkpoint inhibitors, modified bacteria and monoclonal antibodies.

Cytokines aid in immune cell communication and play a big role in the full activation of an immune response. They are given intravesically.

Immune checkpoint inhibitors are drugs that prevent the immune system from slowing down, allowing it to keep up its fight

against the cancer. They are given intravenously through a vein in your arm or a port.

Modified bacteria, such as bacillus Calmette-Guérin (BCG), have been changed to reduce the likelihood that they will not cause a harmful infection while stimulating an immune response. It is given intravesically over multiple weeks followed by a rest period of several weeks (see Figure 2).

Monoclonal antibodies (mAbs) are laboratory-made antibodies designed to target specific tumor antigens, which are specific proteins or other molecules on the surface of tumor cells that may trigger an immune response. In bladder cancer, mAbs target PD-1 or PD-L1 on the surface of the cancer cells.

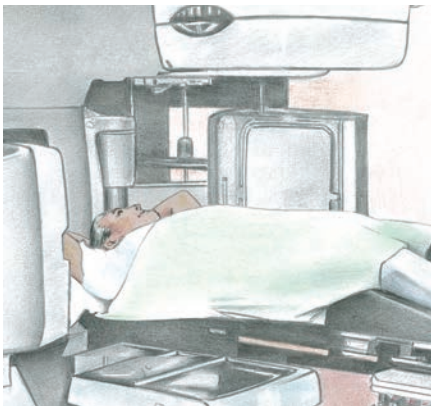
Targeted therapy uses drugs or other substances to identify and attack specific types of cancer cells. Unlike chemotherapy, which attacks healthy cells as well as cancer cells, targeted therapy is designed to affect only cancer cells. The types of targeted therapy approved for bladder cancer include a kinase inhibitor and monoclonal antibodies (mAbs).

A kinase inhibitor may treat some bladder cancers with the fibroblast growth factor receptor (*FGFR2* or *FGFR3*) gene mutation. Data suggest that tumors with mutated *FGFR3* are less likely to be recognized by the immune system, making targeted therapy an option for this gene mutation.

The approved mAbs are antibody-drug conjugates, which mean they consist of a monoclonal antibody that is linked to a chemotherapy drug. Each mAb is designed to target a specific protein on the surface of bladder cancer cells. Once the mAb finds the target on a cancer cell, it connects to it and delivers the chemotherapy drug directly into the cell to destroy it.

Chemoradiation therapy is a treatment approach that combines systemic chemotherapy and pelvic radiation therapy. It may be given after the bladder tumor is removed (using TURBT) or instead of surgery. This treatment approach is considered a "bladder-preservation" option because removal of the bladder may not be necessary if no cancer is detected after treatment. This may be an option for patients whose tumors appear to have been completely removed by TURBT, invaded no deeper than the muscle wall and have not obstructed the ureter.

FIGURE 3
RADIATION THERAPY



External-beam radiation therapy (EBRT) may be used to treat bladder cancer. EBRT uses a machine to direct high-energy beams of radiation at cancer cells inside the body. ©Patient Resource LLC

Radiation therapy uses high-energy radiation to destroy cancer cells and shrink tumors. It may be given with chemotherapy to relieve symptoms or to treat advanced disease. External-beam radiation therapy (EBRT) uses a machine outside the body to send radiation toward the cancer (see Figure 3).

Clinical trials are medical research studies that may offer access to leading-edge treatments not yet widely available. Let your team know if you are open to considering a clinical trial. You can also search on your own. Once you find a potential trial, talk with your doctor. Keep in mind that some may be closed, and you may not qualify for every trial that interests you.

Every participant in a specific trial must meet the same eligibility criteria. Common criteria include cancer type, subtype, stage, biomarker status and treatment history. Your age, gender and other health conditions may also be factors. For example, if a trial requires that you have already had a specific treatment and you have not, you will not be eligible. Ask your doctor if this is an option to consider.

Researchers are evaluating improved ways of performing cystectomies and lymph node dissections, identifying changes to genes or proteins that may lead to bladder cancer, and finding new types of targeted therapy and immunotherapy, or new drug combinations.

DRUG THERAPIES FOR BLADDER CANCER

CHEMOTHERAPY
- cisplatin
- doxorubicin (Adriamycin)
- methotrexate
- mitomycin (Jelmyto, Mitozytrex, Mutamycin)
- thiotepa (Tepadina)
- valrubicin (Valstar)

IMMUNOTHERAPY

Cytokine
- interferon (Roferon-A, Intron A, Alferon)

Immune checkpoint inhibitors
- atezolizumab (Tecentriq)
- avelumab (Bavencio)
- nivolumab (Opdivo)
- pembrolizumab (Keytruda)

Modified bacteria
- bacillus Calmette-Guérin (BCG)

TARGETED THERAPY

Kinase inhibitor
- erdafitinib (Balversa)

Monoclonal antibodies
- enfortumab vedotin-ejfv (Padcev)
- sacituzumab govitecan-hziy (Trodelvy)

SOME POSSIBLE COMBINATIONS
- carboplatin (Paraplatin) and gemcitabine (Gemzar)
- cisplatin and gemcitabine (Gemzar)
- Dose dense (DD)-MVAC (methotrexate, vinblastine [Velban, Velsar], doxorubicin [Adriamycin] and cisplatin)
- MVAC - methotrexate, vinblastine (Velban, Velsar), doxorubicin (Adriamycin) and cisplatin

As of 12/9/21

RECURRENT BLADDER CANCER

It is possible for bladder cancer to return after treatment. This is known as a recurrence and it can happen weeks, months or even years after treatment stops. The potential for recurrence is why follow-up care is so important, (see *Follow-up Care & Healthy Lifestyle*, page 12).

The cancer may return in the same area as the primary cancer or in a different area of the body. Treatment options for recurrent cancer depend on the location and extent of the tumor, treatment history and overall health.

If your bladder cancer returns, your doctor will begin a new cycle of testing to determine any changes in your type of cancer and physical symptoms. A new treatment plan may be developed, and you may add finding a clinical trial to your plan. ■

TERMS to KNOW

You will hear many new words and phrases. These definitions will help.

First-line therapy: The first treatment used.

Second-line therapy: Given when the first-line therapy does not work or is no longer effective.

Standard of care: The best treatment known for the type and stage of cancer you have.

Local treatments: Directed to a specific organ or limited area of the body and includes surgery and radiation therapy.

Systemic treatments: Typically drug therapies such as chemotherapy, immunotherapy and targeted therapy that travel throughout the body.

Intravesical therapy: A type of drug therapy that is injected directly into the bladder.

Choose the diversion plan that fits your lifestyle

After surgical removal of the bladder (radical cystectomy), reconstructive surgery is necessary to provide a new way to store and empty urine. This is called a urostomy, and three options are available. Learn more about each option and discuss with your doctor your preferences regarding urine control. The type of urinary diversion you have will also depend on this input and your medical condition.

OPTION 1: ILEAL CONDUIT

To create this common reconstruction option, the surgeon will isolate a piece of intestine while maintaining the blood vessels that supply the intestine. The surgeon will then attach the ureters (tubes through which urine normally flows from the kidneys to the bladder) to one end of this segment of intestine. The other end will be attached to an incision in your abdominal wall to form a stoma (a surgically-made hole). The surgeon will close the separation in your intestine and all other incisions with sutures (stitches) or staples.

Urine flows continuously through this ileal conduit to the outside, collecting in a small bag (an ostomy bag) attached to the stoma that is emptied periodically. The pouch will lie flat against the body and can be covered with your clothes. This surgery is known as an incontinent diversion because you no longer control the flow of urine from the body.

Your surgeon may insert a small tube(s) into the surgical site to allow any excess fluids to drain during the recovery process. To help drain urine while you heal, stents (small mesh tubes) may be placed through the stoma into the ureters.

OPTION 2: CONTINENT CUTANEOUS POUCH

A continent urinary diversion allows you to have some control over the flow of urine out of your body. To create this internal storage container for urine, the surgeon uses a section of intestine that is attached to your ureters to create a urine storage pouch within the body. This pouch, also referred to as an Indiana pouch, is connected to the ureters on one end and to a stoma on the other. You will drain the pouch by inserting a catheter (small thin tube) through the stoma.

After any stents and catheters are removed, you can empty urine by inserting a catheter through the stoma and draining the urine into the toilet. The stoma and surrounding skin must be washed and dried before and after each catheterization. Initially, the pouch will need to be drained every two to three hours, but over time, you should be able to drain the pouch every four to six hours.

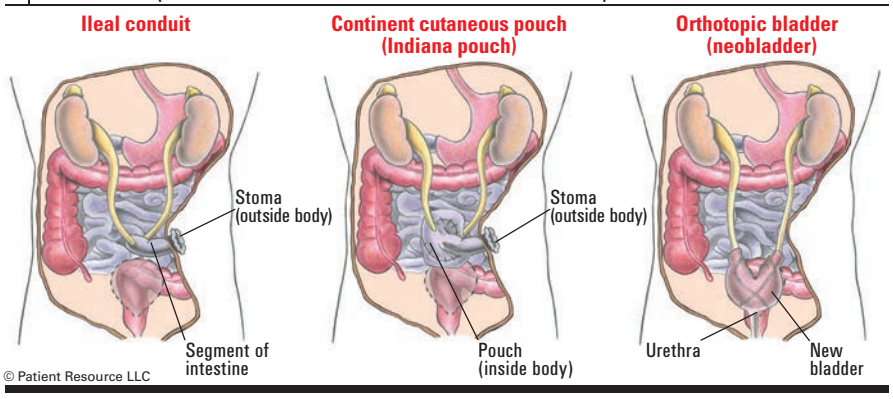
OPTION 3: ORTHOTOPIC BLADDER (NEOBLADDER)

A neobladder, also referred to as a substitute or new bladder, is created using a portion of your intestine. It is a type of internal reservoir for storing urine. One end is attached to the ureters and the other end to the urethra (tube through which urine exits the body). Urine would leave your body in the regular way. An external collection bag is not needed. Over time, you may be able to regain some control of your urination.

To help drain urine while you heal, a catheter and/or stents (small mesh tubes) may be placed into the neobladder through the small incision in the abdomen.

After the catheters are removed, an incontinence pad and an absorbent pad on the bed at night will be necessary until your urinary control improves. Your doctor will give you a urination schedule, which usually begins with urinating every two hours. Bearing down (the Valsalva maneuver), as if having a bowel movement, will cause urination. You may be asked to insert a catheter twice a day after urinating to see if the bladder is emptying completely. The catheter must be irrigated during one of the catheterizations to remove mucus produced by the piece of intestine used to make the neobladder. ■

UROSTOMY (BLADDER REMOVAL AND RECONSTRUCTION)



SURVIVOR VOICES

Mechele Leon, bladder cancer survivor:

"I don't regret my decision to have a urostomy. I belong to a stoma support group with people of all ages. We have young people who have ostomies because of diseases such as irritable bowel syndrome and Crohn's disease. They more than manage. They even swim."

Ann Garner, bladder cancer survivor, on her neobladder.

"After a lot of discussion and prayers, I said 'Let's go for it,' and I've never had a single regret."

Living with a stoma

A stoma is an opening in your abdomen that is connected to your urinary system. A barrier ring may help fill in any gaps. It will be attached to a pouch that lies against your body to collect your urine.

As you get used to the idea of a stoma, keep in mind that most people are able to resume their daily activities – and even wear the same clothes – without many adjustments. Your ostomy nurse will be available to answer your questions. In the meantime, these suggestions may help:

- Always wash your hands with soap and water before and after caring for your stoma and pouch.
- Protect your skin by using the right size pouch and skin barrier opening.
- Change the pouch regularly to avoid leaks and skin irritation.
- Clean the skin around the stoma with water. Pat the skin dry before putting on the skin barrier or pouch.
- You may need to shave the area around your pouch. Hair can prevent the skin barrier from sticking.
- The pouches include filters that should prevent odors. Using fragrance drops or sprays may give you extra confidence.

Services available to assist you through treatment and beyond

Preventing, minimizing and managing the side effects of cancer or its treatment is a primary focus of your multidisciplinary health care team members. Discuss with them the potential physical and emotional side effects of each type of therapy. Ask about any that need immediate attention and find out what to do if they occur. Prompt or even preventive treatment may help avoid serious complications.

Though physical side effects will likely be top of mind, the cancer and its treatment may also affect you emotionally, spiritually and financially. That's why your team will address and manage these challenges by drawing on a range of services known as supportive care.

Following are descriptions of some potentially severe and common side effects (see Table 1). Some side effects may be more intense when therapies are combined.

POTENTIALLY SEVERE SIDE EFFECTS

Severe side effects are not common but can occur with certain types of cancer treatment. Ask your doctor if any therapies in your treatment plan could cause them, and find out how to identify the symptoms. Report them immediately if they occur.

- **Infection** can occur as a result of a low white blood cell count (neutropenia) or other factors. Contact your doctor immediately – do not wait until the next day – if you have any of these symptoms: oral temperature over 100.4° F, chills or sweating; body aches, chills and fatigue with or without fever; coughing, shortness of breath or painful breathing; abdominal pain; sore throat; mouth sores; painful, swollen or reddened skin; pus or drainage from an open cut or sore; pain or burning during urination; pain or sores around the anus; or vaginal discharge or itching. If you cannot reach your doctor, go to the emergency room.
- **Immune-related adverse events** (irAEs) may occur with certain immunotherapy drugs if the immune system becomes overstimulated by treatment and causes inflammation in one or more organs or systems in the body. Some irAEs can develop rapidly, becoming severe and even life-threatening without immediate medical attention.
- **Infusion-related reactions** most frequently occur with treatment given intravenously (IV) through a vein in your arm, usually soon after exposure to the drug. Reactions are generally mild, such as itching, rash or fever. More serious symptoms, such as shaking, chills, low blood pressure, dizziness, breathing difficulties or irregular heartbeat, can be serious or even fatal without medical intervention.

SOME COMMON SIDE EFFECTS

Though most cancer treatments have physical side effects, you likely will not experience all of them (see Table 1). Keep in mind that bladder cancer can impact your sexual desire or sexual performance. Talk to your doctor or nurse about any sexual symptoms. If you feel uncomfortable talking about your sexual health, ask for a referral to an appropriate health care professional or support group.

Supportive care also addresses other challenges that may develop as a result of cancer or its treatment. Other forms of support include the following:

- Dietary
- Fertility
- Financial
- Spiritual or religious
- Transportation

For additional help in an area not listed here, discuss it with a health care professional. ■

TABLE 1
COMMON SIDE EFFECTS OF BLADDER CANCER TREATMENT

Side Effect	Description
Anemia	Abnormally low red blood cell count
Bleeding	Blood in the urine or stool
Blood clots	Leg discomfort
Bowel incontinence	Stool leakage caused by the inability to control bowel movements
Chemo brain (cognitive dysfunction)	Brain fog, confusion and/or memory problems
Constipation	Difficulty passing stools or less frequent bowel movements compared to your usual bowel habits
Decreased appetite	Eating less than usual, feeling full after minimal eating, not feeling hungry
Diarrhea	Frequent loose or watery bowel movements that are commonly an inconvenience but can become serious if left untreated
Erectile dysfunction	An inability to have an erection adequate for sexual intercourse
Eye and vision problems	Blurred vision, dry eyes, eye pain, loss of vision
Fatigue	Tiredness that is much stronger and harder to relieve than the fatigue an otherwise healthy person has
Hair loss (alopecia)	Hair loss on the head, face and body
Infertility	Inability to father a child or become pregnant
Lymphedema	Fluid buildup from lymph node removal that causes swelling
Nausea and vomiting	Stomach upset and/or throwing up
Neuropathy	Numbness, pain, burning sensations and tingling, usually in the hands or feet at first
Neutropenia	Low white blood cell count that increases the risk of infection
Pain	Abdominal, muscular or bone discomfort
Respiratory problems	Shortness of breath (dyspnea) with or without cough, upper respiratory infections
Sexuality issues	Erectile dysfunction, reduced desire or feeling less desirable
Skin reactions	Rash, redness and irritation or dry, flaky or peeling skin that may itch
Thrombocytopenia	Low number of platelets in the blood, which can lead to bruising and bleeding
Urinary discomfort	Pain or burning when urinating
Urinary incontinence	Inability to control the flow of urine from the bladder
Urinary retention	Inability to completely empty the bladder (bladder may feel full even after urinating)
Weight loss	Losing weight unintentionally

A solid plan is key for your physical and mental health

Whether you are still receiving treatment or have finished, you will be checked at regularly scheduled follow-up appointments to monitor for a possible recurrence or other health care issues. These appointments are important because finding any disease recurrence early is key to successful treatment. Along with running tests, your doctor will ask questions about any ongoing physical symptoms you may be having, especially those related to recurrence and continued side effects of treatment.

Your follow-up plan may include:

- An appointment schedule for ongoing monitoring. These appointments may include medical history, a physical exam, imaging procedures (such as X-rays and CT scans), a cystoscopy (if the bladder has not been removed), urine tests, blood work and other lab tests.
- Maintenance medications or therapies, including type, dosage, frequency and duration.
- Referral(s) for cancer rehabilitation, such as physical or occupational therapy, or assistance from a pelvic health specialist.
- Information about your risk of a recurrence, a second cancer, long-term treatment-related side effects and late effects, which are side effects that develop weeks, months or years after treatment ends.
- Recommended screening guidelines for other types of cancer.

Along with reporting physical symptoms, it is also important to discuss how you feel mentally and emotionally — or sooner if something changes. Specific information to discuss includes the following:

- New or ongoing physical symptoms that are not adequately relieved, including pain, gastrointestinal problems, nausea and vomiting, signs of infection and sexual health
- Cognitive (thinking-related) symptoms, such as difficulties with memory, concentration, processing information, word-finding or completing tasks
- Emotional issues, such as depression, anxiety, fear, anger, grief, hopelessness, emotional numbness, feeling overwhelmed or other concerns
- Visits to the emergency room, urgent care or other doctors, even if not cancer-related

HEALTHY LIFESTYLE

Having a well-balanced lifestyle may help you tolerate treatment better, lower the risk of a recurrence or the risk of other chronic diseases, and help protect against secondary cancers. Following are suggestions for smart ways to approach key elements of your everyday life.

- Follow a nutritious, heart-healthy diet that includes a variety of fruits and vegetables, lean meat, low-fat dairy products and foods with plenty of fiber. Ask your doctor to recommend a registered dietician who can help you plan meals and make good food choices.
- Watch your weight. It may be difficult to maintain your appetite, which may lead to weight loss.
- Get regular exercise. Even walking 10 minutes a day can provide benefits.
- Stay hydrated. In general, drinking 8 to 10 glasses of fluid a day is recommended. Sometimes you may need more. Dehydration can worsen side effect symptoms.
- Avoid processed and red meats.

INCONTINENCE

Difficulty with urination may occur after treatment for bladder cancer. Incontinence, or leakage of urine, can range from mild to severe. There are three types of incontinence:

- Stress incontinence happens when the muscle that squeezes the urethra to keep urine in the bladder is weak or damaged, or the nerves that help the muscle work have been damaged.
- Overflow incontinence occurs when the bladder does not empty well and the amount of urine made is more than the bladder can hold. Usually caused by a blockage or narrowing caused by scar tissue, overflow incontinence may happen when the bladder muscle cannot squeeze well enough to release all the urine.
- Urge incontinence is the most common type after radiation therapy. The symptoms are similar to that of an overactive bladder. The bladder muscle, irritated by the radiation, contracts too often, sometimes powerfully enough to force urine out with little warning.

Below are some options for managing incontinence.

- Pelvic floor exercises, commonly known as Kegels (pronounced KEE-gulz), can help reduce leakage from stress incontinence (see *About Kegels* below).
- Medications that will tighten or relax your muscles may be prescribed. These drugs can have side effects, so make sure to ask about them.
- For overflow incontinence caused by blockage of the urethra by scar tissue or by an enlarged prostate, a surgical procedure done through a scope can relieve the obstruction.
- In serious cases of stress incontinence, the surgeon may implant a sling to hold up the bladder or place an artificial urinary sphincter (device that constricts) around the urethra to prevent or reduce leakage.
- Empty your bladder on a regular schedule and before physical activities to help prevent leakage.

Other lifestyle changes may include:

- Avoiding lifting heavy objects
- Practicing lengthening the time between trips to the bathroom to train your bladder
- Eating a healthy diet ■

ABOUT KEGELS

Exercises to help manage incontinence

➥ **Kegels are helpful before and after bladder cancer treatment. These exercises may not eliminate your bladder incontinence, but with consistent practice, you could see a marked improvement in just weeks. Do not practice them if you have a catheter in place.**

To get started, try to perform these exercises while you are standing. If you are not able to stand, try sitting or choose a position that is comfortable for you.

1. **Tighten your pelvic floor muscles. Ensure you're flexing the correct muscles (not your abdomen, thighs or buttocks). Tighten the muscles used to stop urinating mid-flow.**
2. **Hold the contraction for 10 seconds, and then relax for 10 seconds. Avoid holding your breath. Instead, breathe freely during the exercises.**
3. **Aim for at least six sets of 10 repetitions a day. As your muscles get stronger, increase your repetitions daily.**

Support and financial resources available for you

BLADDER CANCER

American Bladder Cancer Society ..... www.bladdercancersupport.org
Bladder Cancer Advocacy Network ..... www.bcan.org
United Ostomy Associations of America, Inc ..... www.ostomy.org

CANCER EDUCATION

American Cancer Society ..... www.cancer.org
American Society of Clinical Oncology ..... www.cancer.net
CANCER101 ..... www.cancer101.org
Cancer*Care* ..... www.cancercare.org
Cancer Support Community ..... www.cancersupportcommunity.org
Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov
FORCE: Facing Our Risk of Cancer Empowered ..... www.facingourrisk.org
The Gathering Place ..... www.touchedbycancer.org
Get Palliative Care ..... www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) ..... www.cancergrace.org
The Hope Light Foundation ..... www.hopelightproject.com
LLS | PearlPoint Nutrition Services ..... www.pearlpoint.org
National Cancer Institute ..... www.cancer.gov
National Comprehensive Cancer Network (NCCN) ..... www.nccn.org
National LGBT Cancer Network ..... www.cancer-network.org
NCI Cancer Information Service 800-422-6237
OncoLink ..... www.oncolink.org
Patient Resource ..... www.patientresource.com
Scott Hamilton CARES Foundation ..... www.scottcares.org
Triage Cancer ..... www.triagecancer.org
Union for International Cancer Control ..... www.uicc.org
U.S. National Library of Medicine ..... www.nlm.nih.gov

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program www.4thangel.org, 866-520-3197
CanCare ..... www.cancare.org, 888-461-0028
CANCER101 ..... www.cancer101.org, 646-638-2202
Cancer and Careers ..... www.cancerandcareers.org, 646-929-8032
Cancer*Care* ..... www.cancercare.org, 800-813-4673
Cancer Connection ..... www.cancer-connection.org, 413-586-1642
Cancer Hope Network ..... www.cancerhopenetwork.org, 877-467-3638
Cancer Really Sucks! ..... www.cancerreallysucks.org
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
Cancer Survivors Network ..... csn.cancer.org, 800-227-2345
Caregiver Action Network ..... www.caregiveraction.org, 855-227-3640
CaringBridge ..... www.caringbridge.org
Center to Advance Palliative Care ..... www.capc.org
Chemo Angels ..... www.chemoangels.com
Cleaning for a Reason ..... www.cleaningforareason.org
Connect Thru Cancer ..... www.connectthrucancer.org
Cooking with Cancer ..... www.cookingwithcancer.org, 205-978-3570
Family Caregiver Alliance ..... www.caregiver.org, 800-445-8106
Friend for Life Cancer Support Network www.friend4life.org, 866-374-3634
The Gathering Place ..... www.touchedbycancer.org, 216-455-1517
Imerman Angels ..... www.imermanangels.org, 866-463-7626
Livestrong Foundation ..... www.livestrong.org, 855-220-7777
LivingWell Cancer Resource Center ..... www.livingwellcrc.org, 630-933-7860
Lotsa Helping Hands ..... www.lotsahelpinghands.com
The Lydia Project ..... www.thelydiaproject.org, 877-593-4212
MyLifeLine ..... www.mylifeline.org, 888-793-9355
National LGBT Cancer Project ..... www.lgbtcancer.org, 212-673-4920
Patient Empowerment Network ..... www.powerfulpatients.org
SHARE Caregiver Circle ..... www.sharecancersupport.org/caregivers-support, 844-275-7427
Stronghold Ministry ..... www.mystronghold.org, 877-230-7674
Triage Cancer ..... www.triagecancer.org, 424-258-4628
Walk With Sally ..... www.walkwithsally.org, 310-322-3900
Well Spouse Association ..... www.wellspouse.org, 732-577-8899
weSPARK Cancer Support Center ..... www.wespark.org, 818-906-3022
Wigs & Wishes ..... www.wigsandwishes.org

CLINICAL TRIALS

Cancer Support Community ..... www.cancersupportcommunity.org/find-clinical-trial, 888-793-9355
Center for Information & Study on Clinical Research Participation ..... www.searchclinicaltrials.org
ClinicalTrials.gov ..... www.clinicaltrials.gov
Lazarex Cancer Foundation ..... www.lazarex.org, 877-866-9523, 925-820-4517
National Cancer Institute ..... www.cancer.gov/clinicaltrials, 800-422-6237
WCG CenterWatch ..... www.centerwatch.com, 866-219-3440

NUTRITION

American Cancer Society ..... www.cancer.org, 800-227-2345
Cancer*Care* ..... www.cancercare.org, 800-813-4673
Cancer Support Community ..... www.cancersupportcommunity.org, 888-793-9355
LLS | PearlPoint Nutrition Services ..... www.pearlpoint.org
Physicians Committee for Responsible Medicine ..... www.pcrm.org/health-topics/cancer

PATIENT ADVOCACY

American Cancer Society Cancer Action Network ..... www.fightcancer.org
Cancer Legal Resource Center ..... www.thedrlc.org/cancer
Cancer Support Community ..... www.cancersupportcommunity.org
Dream Foundation ..... www.dreamfoundation.org
Firefighter Cancer Support Network ..... www.firefightercancersupport.org
Friend for Life Cancer Support Network www.friend4life.org, 866-374-3634
The Gathering Place ..... www.touchedbycancer.org
LivingWell Cancer Resource Center ..... www.livingwellcrc.org
National Coalition for Cancer Survivorship ..... www.canceradvocacy.org
Office of Cancer Survivorship ..... www.cancercontrol.cancer.gov/ocs
Patient Advocate Foundation ..... www.patientadvocate.org
Research Advocacy Network ..... www.researchadvocacy.org

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Astellas Pharma Support Solutions ..... astellaspharmasupportsolutions.com/patient/padcev, 800-477-6472
Balversa Support ..... www.janssencarepath.com/patient/balversa/cost-support, 877-227-3728
Bavencio CoverOne Patient Access ..... www.coverone.com/en/Patient_Assistance.html, 844-826-8371
Bristol-Myers Squibb ..... bms.com/patient-and-caregivers/get-help-paying-for-your-medicines, 800-721-8909
Bristol-Myers Squibb Access Support ..... www.bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation ..... bmspaf.org, 800-736-0003
EMD Serono Patient Support Programs ..... www.emdserono.com/us-en/patients-and-caregivers/get-help-paying-for-your-medication.html, 844-826-8371
Endo Pharmaceuticals (Valstar) ..... valstarsolution.com/pdf/VL-03020a2_SRE_HUB_Info_Form.pdf, 800-462-3636
Genentech Access Solutions ..... www.genentech-access.com/patient/brands/tecentriq, 877-436-3683
Janssen CarePath ..... www.janssencarepath.com, 877-227-3728
Jelmyto UroGen Support ..... www.jelmyto.com/pdf/patient-enrollment-form.pdf, 855-535-6986
Johnson & Johnson Patient Assistance Foundation ..... www.jjpaf.org, 800-652-6227
Keytruda Financial Help ..... www.keytruda.com/financial-support/, 855-257-3932
Merck Access Program ..... www.merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Merck Helps ..... www.merckhelps.com/keytruda, 800-727-5400
Otrexup TotalCare Support Program ..... www.oxtrexup.com/patient-resources, 800-422-5604
Padcev Support Solutions ..... www.padcev.com/padcev-support-solutions, 888-402-0627
Pfizer RxPathways ..... www.pfizerrxpathways.com, 844-989-7284
Rasuvo (methotrexate) CORE Connections ..... www.rasuvo.com/patient-resources/prescription-savings, 855-336-3322
Tecentriq Patient Assistance Tool ..... www.genentech-access.com/patient/brands/tecentriq, 877-436-3683
Trodelvy Access Support ..... www.trodelvy.com/bladder-cancer/access-support, 844-876-3358

SURVIVORSHIP

13thirty Cancer Connect www.13thirty.org
A Time to Heal Cancer Foundation ..... www.atimetohealfoundation.org
Angel On My Shoulder ..... angelonmyshoulder.org
Cactus Cancer Society ..... www.cactuscancer.org
Cancer ABCs ..... www.cancerabcs.org
Cancer and Careers ..... www.cancerandcareers.org, 646-929-8032
Cancer Survivors Network ..... csn.cancer.org, 800-227-2345
Centers for Disease Control and Prevention (CDC) ..... www.cdc.gov/cancer/survivors
Global Resource for Advancing Cancer Education (GRACE) ..... www.cancergrace.org
Indian American Cancer Network ..... www.iacannetwork.org
National Cancer Survivors Day ..... www.ncsd.org
National Coalition for Cancer Survivorship ..... www.canceradvocacy.org
Stupid Cancer ..... www.stupidcancer.org

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