# Educated Patient®

# Ovarian Cancer

# RESOURCE GUIDE



Presented by

CUTC®

A collection of resources that provide information and support for patients and the professionals who treat them.

# What would I do with more time progression-free?

With Zejula® (niraparib), you have a choice about what comes next.

If you've had 2 or more courses of platinum-based chemotherapy for **epithelial ovarian**, **fallopian tube**, **or primary peritoneal cancer**, and it has responded completely or partially to your most recent treatment, **ZEJULA may be right for you**.

**ZEJULA** is an oral, once-daily maintenance treatment taken with or without food that works to keep cancer cells from repairing themselves. This causes cancer cells to die, and may slow the return or progression of cancer.

ZEJULA can also affect other cells and tissues in the body.

Taking ZEJULA could mean more time to spend with your family, more time to travel, renew an old friendship, or start a new project. Taking ZEJULA could mean more time to live progression-free.

### What is ZEJULA?

ZEJULA is a prescription medicine used for the maintenance treatment of adults with ovarian cancer, fallopian tube cancer, or primary peritoneal cancer, when the cancer comes back. ZEJULA is used after the cancer has responded (complete or partial response) to treatment with platinum-based chemotherapy.

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

Before taking ZEJULA, tell your healthcare provider about all of your medical conditions, including if you:

- have heart problems.
- have high blood pressure.
- are pregnant or plan to become pregnant. ZEJULA can harm your unborn baby and may cause loss of pregnancy (miscarriage).
- If you are able to become pregnant, your healthcare provider may perform a pregnancy test before you start treatment with ZEJULA.
- Females who are able to become pregnant should use effective birth control (contraception) during treatment with ZEJULA and for 6 months after the last dose of ZEJULA. Talk to your healthcare provider about birth control methods that may be right for you.
- Tell your healthcare provider right away if you become pregnant.
- are breastfeeding or plan to breastfeed. It is not known if ZEJULA passes into your breast milk. Do not breastfeed during treatment with ZEJULA and for 1 month after the last dose of ZEJULA.
   Talk to your healthcare provider about the best way to feed your baby during this time.

**Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements.

# What is the most important information I should know about ZEJULA?

ZEJULA may cause serious side effects including:

Bone marrow problems called Myelodysplastic Syndrome (MDS) or a type of cancer of the blood called Acute Myeloid Leukemia (AML). Some people who have ovarian cancer and who have received previous treatment with chemotherapy or certain other medicines for their cancer have developed MDS or AML during treatment with ZEJULA. MDS or AML may lead to death. If you develop MDS or AML, your healthcare provider will stop treatment with ZEJULA.

Symptoms of low blood cell counts (low red blood cells, low white blood cells, and low platelets) are common during treatment with ZEJULA, but can be a sign of serious bone marrow problems, including MDS or AML. Symptoms may include:

- weakness
- fever
- feeling tired
- shortness of breath
- weight loss
- blood in urine or stool
- frequent infections
- bruising or bleeding more easily

Your healthcare provider will do blood tests to check your blood cell counts:

- before treatment with ZEJULA
- weekly for the first month of treatment with ZEJULA
- every month for the next 11 months, then as needed during treatment with ZEJULA
- High blood pressure. High blood pressure is common during treatment with ZEJULA, and can become serious. Your healthcare provider will check your blood pressure and heart rate monthly for the first year and as needed thereafter during your treatment with ZEJULA.

# I'll do more than watch and wait. I'll Start Something.

### In the clinical trial, ZEJULA offered more time living progression-free.

- Half of the women who took ZEJULA and had an inherited BRCA mutation (BRCA-positive) experienced disease progression after 21.0 months, compared with 5.5 months for those who did not receive ZEJULA
- Half of the women who took ZEJULA and did not have an inherited BRCA mutation (BRCA-negative) experienced disease progression after 9.3 months, compared with 3.9 months for those who did not receive ZEJULA

Progression-free survival (PFS) is the length of time during and after chemotherapy that you live with cancer but your disease does not get worse.

# Visit ZEJULA.com/myway to sign up for more information about maintenance treatment with ZEJULA.

### What are the possible side effects of ZEJULA?

ZEJULA can cause serious side effects, including:

 See "What is the most important information I should know about ZEJULA?"

The most common side effects of ZEJULA include:

- · heart not beating regularly
- nausea
- constipation
- vomiting
- pain in the stomach area
- mouth sores
- diarrhea
- indigestion or heartburn
- dry mouth
- tiredness
- loss of appetite
- urinary tract infection

- changes in liver function blood tests
- pain in your joints, muscles, and back
- headache
- dizziness
- change in the way food tastes
- trouble sleeping
- anxiety
- sore throat
- shortness of breath
- cough
- rash

Your healthcare provider may change your dose, temporarily stop, or permanently stop treatment with ZEJULA, if you have certain side effects.

These are not all the possible side effects of ZEJULA. For more information, ask your healthcare provider or pharmacist.

Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

### How should I take ZEJULA?

- Take ZEJULA exactly as your healthcare provider tells you to.
- Take ZEJULA 1 time each day, at the same time each day.
- ZEJULA may be taken with or without food.
- ZEJULA capsules should be swallowed whole.
- Taking ZEJULA at bedtime may help relieve any nausea symptoms you may have.
- Do not stop taking ZEJULA without first talking with your healthcare provider.
- If you miss a dose of ZEJULA, take your next dose at your scheduled time. Do not take an extra dose to make up for a missed dose.
- If you vomit after taking a dose of ZEJULA, do not take an extra dose. Take your next dose at your scheduled time.
- If you take too much ZEJULA, call your healthcare provider or go to the nearest hospital emergency room right away.

Please see additional Important Safety Information on the following page.



### How should I store ZEJULA?

Store ZEJULA at room temperature between 68° to 77°F (20° to 25°C).

Keep ZEJULA and all medicines out of the reach of children.

### General information about the safe and effective use of ZEJULA.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use ZEJULA for a condition for which it was not prescribed. Do not give ZEJULA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your healthcare provider or pharmacist for information about ZEJULA that is written for health professionals.

### Indication

ZEJULA (zuh-JOO-luh) is a prescription medicine used for the maintenance treatment of adults with ovarian cancer, fallopian tube cancer, or primary peritoneal cancer, when the cancer comes back. ZEJULA is used after the cancer has responded (complete or partial response) to treatment with platinum-based chemotherapy. It is not known if ZEJULA is safe and effective in children.

### **Important Safety Information**

ZEJULA may cause serious side effects, including:

Bone marrow problems called Myelodysplastic Syndrome (MDS) or a type of blood cancer called Acute Myeloid Leukemia (AML). Some people who have ovarian cancer and who have received previous treatment with chemotherapy or certain other medicines for their cancer have developed MDS or AML during treatment with ZEJULA. MDS or AML may lead to death.

Symptoms of low blood cell counts (low red blood cells, low white blood cells, and low platelets) are common during treatment with ZEJULA, but they can be a sign of serious bone marrow problems, including MDS or AML. These symptoms may include the following:

- Weakness
- Feeling tired
- Weight loss
- Frequent infections
- Fever

- Shortness of breath
- Blood in urine or stool
- Bruising or bleeding more easily

Your doctor will do blood tests to check your blood cell counts before treatment with ZEJULA. You will be tested weekly for the first month of treatment with ZEJULA, monthly for the next 11 months of treatment, and from time to time afterward.

**High blood pressure** is common during treatment with ZEJULA, and it can become serious. Your doctor will check your blood pressure and heart rate monthly for the first year during your treatment with ZEJULA and as needed afterward. Your doctor may lower the dose of ZEJULA to treat high blood pressure.

Before starting to take ZEJULA, tell your doctor about all of your medical conditions, including if you:

- Have heart problems
- Have high blood pressure
- Are pregnant or plan to become pregnant. ZEJULA may harm an unborn baby and may cause loss of pregnancy (miscarriage)



- If you are able to become pregnant, you should use effective birth control (contraception) during treatment with ZEJULA and for 6 months after taking the last dose of ZEJULA
- If you are able to become pregnant, your doctor may perform a pregnancy test before you start treatment with ZEJULA
- You should tell your doctor right away if you become pregnant
- · Are breastfeeding or plan to breastfeed
  - ZEJULA may harm your baby. You should not breastfeed your baby during treatment with ZEJULA and for 1 month after taking the last dose of ZEJULA

**Tell your doctor about all the medicines you take**, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

### The most common side effects of ZEJULA include the following:

- Heart not beating regularly
- ° Nausea
- ° Constipation
- Vomiting
- ° Pain in the stomach area
- ° Mouth sores
- Diarrhea
- ° Indigestion or heartburn
- o Dry mouth
- Tiredness
- ° Loss of appetite
- Urinary tract infection
- Shortness of breath

- Cough
- ° Rash
- Changes in liver function blood tests
- Pain in your joints, muscles, and back
- Headache
- Dizziness
- Change in the way food tastes
- Trouble sleeping
- Anxiety
- ° Sore throat

If you have certain side effects, then your doctor may change your dose of ZEJULA, temporarily stop your treatment with ZEJULA, or permanently stop treatment with ZEJULA.

These are not all the possible side effects of ZEJULA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Please see the Prescribing Information at ZEJULA.com.

# What if I need support affording ZEJULA?

TOGETHER with TESARO™: a patient resource program from TESARO, the company that developed ZEJULA, that supports women taking TESARO medications. The program offers a dedicated group of access and affordability experts to help you access, pay for, and stay on ZEJULA. TOGETHER with TESARO also offers educational tools, links to patient advocacy groups, co-pay and transportation resources, and other patient and care partner resources. Learn more about the individualized suite of solutions at TOGETHERwithTESARO.com or by calling 844-2TESARO (844-283-7276) from 8 AM to 8 PM ET.



### PATIENT INTRODUCTION

# A Life Changed by Ovarian Cancer

Ovarian cancer crept into my life with illusive persistence. At the time of my diagnosis, I had already endured months of pain and anxiety. My symptoms were the classic ovarian cancer symptoms: nausea, diarrhea, constipation, frequent urination, unusual fatigue, and general abdominal discomfort, bloating and fullness after meals.

My relationships were changing and my emotions were in a constant state of turmoil. I was seeing my primary care physician (PCP) at least once or twice a month — and some months as many as 3 times! Every time I saw my PCP, I would describe my symptoms. She was giving me everything from drugs for acid reflux and nausea to antibiotics for kidney and urinary tract infections.

I knew something was wrong with me. I had several emergency room visits in late 2005 and early 2006. I would leave them and every doctor's visit with no answers, but knowing something was wrong. I could feel it.

I believe that if I had known about ovarian cancer, the symptoms and the lack of diagnostic testing, I would have been more vigilant. I would have realized that the changes in my body were not "silent," but were there to make me pay attention.

It wasn't until early 2006 that things started to come together. I was given a diagnosis of ovarian cancer; specifically, a diagnosis of a germ cell tumor called endodermal yolk sac that is rare for someone my age (39). Everything happened to me relatively quickly, from diagnosis to surgery to chemo in less than a month. The next four months were tough for me and everybody around me. But we got through it and eventually my cancer went into remission.

Twelve years later, it's mind-boggling how far removed I am from my ovarian cancer diagnosis, and yet how close I remain. I still can't believe that was me: chemo-bound, bald and scared out of my mind. I don't ever want to lose my connection with ovarian cancer. I hate it ... but I love who I have become because of it.

Having a disease like ovarian cancer has provided me an opportunity to reevaluate my life. My world has



become broader. I have had the pleasure of meeting ovarian cancer survivors from throughout the country. I have done television interviews, written newspaper and magazine articles, been interviewed for a podcast and done numerous health fairs.

I have a story that needs to be shared so that others will not feel alone in their fight against ovarian cancer. I look to the future and vow to make the best life I can for myself and those I care about. In the process, I hope to touch the lives of others with some of the compassion and love I was given.

For survivorship to be meaningful to me, it requires a certain level of lasting responsibility.

There seems to be no rhyme or reason to this insidious disease. Even so, I am glad that I can provide some help and support based on my own journey. I have a responsibility to make the best use of my life and to help as many women as I can live strong lives with ovarian cancer.

The more I do, the more I want to do.

- Kim, ovarian cancer survivor

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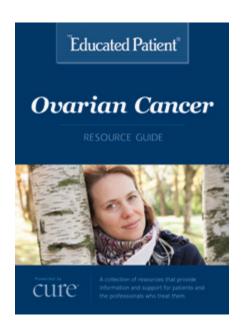
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# Information About Ovarian Cancer

Ovarian cancer starts in the ovaries, the two small, round organs on either side of the uterus that store reproductive eggs and produce the hormones estrogen and progesterone. 1,2 According to the Centers for Disease Control and Prevention (CDC), more than 20,000 women in the United States develop ovarian cancer each year. Although accounting for only 3 percent of all cancers that occur in women, ovarian cancer results in more deaths than any other cancer related to the female reproductive system. For women in the United States, ovarian cancer is the 10th most common cancer and fifth most common cause of cancer-related death. 3

When the disease is identified and treated early, as many as 90 percent of those diagnosed live beyond the five-year milestone. However, early stage ovarian cancer accounts for less than 20 percent of diagnoses. Causes of ovarian cancer remain unknown, but more information has emerged regarding risk factors. All women are at risk for developing ovarian cancer, but older women are more likely to be diagnosed than younger women. According to the CDC, the highest number of ovarian cancers occur in women aged 60 years or older, and approximately 90 percent of women who have ovarian cancer are older than 40.1

# Types of Ovarian Cancer and Risks of Recurrence

There are over 30 different types of ovarian cancer, with three that are particularly common<sup>4</sup>:

- Epithelial: This type of ovarian cancer develops from cells that cover the surface of the ovary.
   This is the most common type, accounting for 85 to 90 percent of all ovarian cancers, and the most dangerous.
- Germ: This type of ovarian cancer develops from cells that are destined to form eggs. Most germ cell tumors are noncancerous, although some could still be cancerous and dangerous. Approximately 90 percent of patients with ovarian germ cell cancer can be cured and preserve fertility.
- Stromal: This type of ovarian cancer develops from cells that release hormones and form tissue connections to the ovaries. This type is rare, with approximately 70 percent presenting in the early stages, in which cancer is limited to one or both ovaries.

Importantly, patients who are treated for ovarian cancer may also be at risk for recurrence.<sup>5</sup> Approximately 70 percent of patients diagnosed with ovarian cancer will have recurrence and risk increases with the stage of the cancer at the time of diagnosis.

### **Risk Factors for Ovarian Cancer**

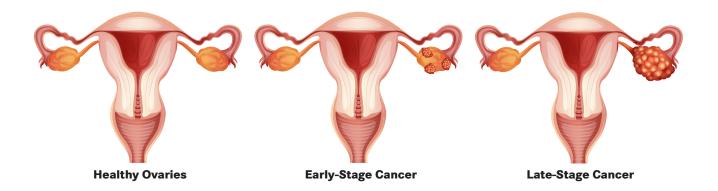
The following factors may increase the risk of ovarian cancer<sup>1</sup>:

- Older age (middle age or older)
- · Family history of ovarian cancer
- · Previous breast, uterine or colorectal cancer
- Eastern European background
- Early menses, difficulty with pregnancy or never giving birth
- Endometriosis (tissue from the uterus lining grows in other parts of the body)
- Inherited gene mutations (BRCA 1 and 2)

Additionally, some research suggests that gene mutations related to ovarian cancer are not related, but rather acquired during a woman's lifetime. Changes to the TP53 tumor suppressor gene or the HER2 oncogene could help predict a patient's prognosis. However, the cause of these acquired gene mutations is unknown and requires further investigation.<sup>6</sup>

Even if you have one or more of these risk factors, you may not necessarily get ovarian cancer. However, it is best to be cautious and speak with your doctor and health care providers about your individual risk. Although there is no guaranteed method to prevent ovarian cancer, certain factors may reduce risk 1.6.7:

- · Birth control pills
  - Women who have taken birth control pills for three to six months may have a lower risk of ovarian cancer. The risk may become lower with longer durations of use, and the beneficial effect lasts for several years even after the pill is discontinued.
- · Pregnancy and giving birth
  - Women who have been pregnant and given birth before the age of 26 may have a lower risk of ovarian cancer compared with women who have not. With each full-term pregnancy, the risk of ovarian cancer is reduced.



- Gynecologic surgery
  - Tubal ligation (tying your tubes), hysterectomy (surgically removing the uterus) and oophorectomy (removing ovaries) may lower the risk of ovarian cancer.
- Breastfeeding
  - Studies have suggested that women who breastfeed for longer than a year may have a lower risk of ovarian cancer.

### **Signs and Symptoms**

It is important to pay attention to your body and recognize the potential signs and symptoms of ovarian cancer as soon as possible. If you notice unusual and unexplained changes, it is best to contact your doctor.<sup>1</sup>

Possible signs and symptoms of ovarian cancer to watch for 1,8:

- Pain or pressure in the area below your stomach and between your hip bones (pelvic/abdominal area)
- Back pain
- Bloating
- Changes in appetite (feeling full too quickly or having difficulty with eating)
- Frequent urination and/or constipation

Signs and symptoms of ovarian cancer may be general and difficult to identify. Only 19 percent of ovarian cancers are diagnosed in early stages. Therefore, it is essential to notice if your symptoms are persistent and do not resolve after normal management with diet change, exercise, or rest. If you experience any of these signs and symptoms for longer than two weeks, contact your doctor. Although these symptoms may be caused by something other than ovarian cancer, it is best to discuss possible reasons with your doctor.

### **Diagnosis**

For women who do not experience signs or symptoms, it may be difficult to diagnose ovarian cancer. Currently, there is no simple and reliable way to test for ovarian cancer other than noticing abnormal signs and symptoms. A normal pelvic exam will typically not identify ovarian cancer unless the doctor discovers that the ovary is enlarged. The Pap test, which samples cells from the cervix, can only screen for cervical cancer and not ovarian cancer.

Although there is no simple and reliable screening test specifically for detecting ovarian cancer, other tests may help with identifying ovarian cancer and can be offered by your doctor<sup>9</sup>:

- Pelvic exam: Women aged 18 and older should undergo an annual vaginal exam and women aged 35 and older should undergo an annual rectovaginal exam. During a rectovaginal exam, the physician examines the rectum and vagina by feeling for abnormal swelling and tenderness.
- Transvaginal sonography: An ultrasound where a small instrument is inserted into the vagina. This test may be appropriate for women with an abnormal pelvic exam and may be at high risk for ovarian cancer.
- CA-125 blood test: CA-125 is a protein produced by ovarian cancer cells, and the CA-125 level can be elevated in the blood of a woman at high risk for ovarian cancer. Although CA-125 is an important test, increased levels may not always point to ovarian cancer. Sometimes, ovarian cancers will not elevate CA-125 levels high enough to result in a positive test. Additionally, other noncancerous ovarian diseases could also elevate CA-125 levels.

These tests may be useful for women with unexplained signs or symptoms of ovarian cancer, previous breast, uterine or colorectal cancer, or have a close relative with ovarian cancer.<sup>1</sup>

### **Treatment Options**

### Surgery

Surgical removal of the cancerous growth is the most common method of treatment. Most women who have ovarian cancer will undergo surgery during their disease course. The amount of surgery required depends on the patient's overall health and how far the cancer has spread to other parts of the body. It is recommended that a gynecologic oncologist performs the surgery, as they are specialists with additional training. <sup>10,11</sup>

Surgery may involve staging, which means identifying how far the cancer has spread. Staging may include performing a hysterectomy, an operation that removes the uterus, or a bilateral salpingo-oophorectomy, an operation that removes both ovaries and fallopian tubes. For women who have ovarian cancer in its earliest stage, it may be possible to treat the disease without having to remove the uterus or both ovaries.<sup>11</sup>

Another important goal of surgery is debulking, which means to remove as much of the cancerous tumor as possible. Surgical debulking is important to women whose ovarian cancer has widely spread throughout the abdomen. Optimal debulking occurs when tumors greater than 1 cm are eliminated and may involve removing pieces of the bladder, spleen, gallbladder, liver, stomach or pancreas. Women who have had cancerous tumors optimally debulked may have a better prognosis compared with women who have larger tumors remaining after surgery.<sup>11</sup>

### Chemotherapy

Chemotherapy treats cancer by using chemicals that may kill cancer cells or prevent them from growing.<sup>11</sup> Usually, chemotherapy is a systemic treatment, which means the medication can enter the bloodstream and reach all parts of the body. Chemotherapy agents can be given by mouth, injected into a vein or injected through a catheter, which is a thin tube that can be connected into the abdominal cavity.<sup>12,13</sup>

Treatment for ovarian cancer usually involves a combination of two or more chemotherapy agents and

is administered every three to four weeks. Generally, treatment for ovarian cancer takes three to six cycles, which are scheduled doses of medication followed by periods of recovery, but this duration may vary depending on the type of chemotherapy. Ask your doctor for more information on the type and duration of chemotherapy you may receive.<sup>13</sup>

### Targeted Therapy

As a newer type of treatment option, targeted therapy works by identifying and attacking cancer cells while trying to minimize the damage on normal, healthy cells. Targeted therapy functions by attacking the inner mechanisms or processes (called pathways) of cancer cells, which are different from those of normal cells. There are various types of targeted therapy that work on different pathways or cell mechanisms, but generally will affect a cancer cell's growth, division, repair processes, or interactions with other cells. 14

### Radiation

Radiation therapy uses high-energy X-rays that shrink tumors by killing cancer cells. Most often, the radiation therapy used to treat ovarian cancer is a tightly focused stream that targets the cancer directly. Although it is no longer commonly used for treating ovarian cancer in the United States, radiation therapy can be used to treat areas of the body where the cancer has spread.<sup>15</sup>

### Hormone Therapy

Hormone therapy involves using medication that mimics or in some cases, blocks hormones, to treat cancer. Hormone therapy is not typically used for epithelial ovarian cancer, which is the most common type of cancer that affects the outer surface of the ovary, but may be used to treat ovarian stromal cancer, a rare type that affects the connective tissues surrounding the ovary. 4,16

### Clinical Trials

Clinical trials are research studies that investigate new treatments or procedures in a controlled setting. In some cases, clinical trials may represent the only opportunity for patients to access new treatments that have shown promise. However, clinical trials may not be appropriate for everyone. Talk to your doctor to find out if you may be a candidate for clinical trials.<sup>17</sup>

# **Health, Diet and Emotional Support**

Ovarian cancer may cause a variety of symptoms that affect your daily life. However, there are lifestyle modifications that you can make to maintain your quality of life. This section provides health tips and diet suggestions to help manage your condition, but it is also important to talk to your doctor before beginning anything new.

### Health

When undergoing cancer treatment, it is common to feel fatigue, or extreme tiredness. Fatigue differs from normal tiredness because people may still feel exhausted even after resting. Some may experience fatigue even after treatment, and this tiredness can make it difficult to do normal daily activities. <sup>18</sup> Although it may be difficult initially, studies have shown that exercise can help reduce fatigue. Individuals who follow an exercise program designed for individual needs tend to feel better both physically and emotionally. If you are unable to stay active during treatment and have not exercised in some time, it is normal for your strength to decline. It is advisable to start slowly, such as taking short walks. <sup>18</sup>

Your exercise schedule should be created to fit your abilities. While exercising, be sure to listen to your body. If you become very tired, it is OK to rest. It may be helpful to find a friend who is willing to do the exercises with you. Involving friends or family may help motivate you to be consistent with your exercise program. Importantly, talk with your doctor and health care professionals regarding your plans for physical activity before initiating any exercise. <sup>18</sup>

Along with increasing physical activity, it is important to care for your health in other ways. It may be beneficial to decrease alcohol consumption, attempt to quit smoking and tobacco products and reduce stress in your life. Your doctor or health care provider can help you create a plan for important lifestyle changes. <sup>18</sup>

### **Diet**

After cancer treatment, it may be frustrating trying to eat healthy. Treatment may affect your sense of taste, make you nauseous, alter your appetite, and cause you to lose or gain weight. It may be helpful to eat small portion sizes every two to three hours until you can eat larger meals. The American Cancer Society recommends



eating a variety of healthy foods including 2½ cups of fruits and vegetables daily as well as whole grain foods from bread, rice, beans and more. Additionally, you can ask your doctor and health care team about seeing a dietitian, an expert in nutrition who can help you with eating habits and managing treatment side effects. Developing and maintaining good eating habits is important to lower your risk for several types of cancers and offers overall health benefits.

### **Emotional Support**

When treatment ends, you may experience a wide variety of emotions. While you were undergoing treatment, your thoughts may have been focused on your treatment and discussing with your health care team. 19 Now that you have returned home, you may feel other issues catching up to you and have extra time on your hands. For some individuals, these changes can cause anxiety.

Almost everyone who has experienced cancer treatment may benefit from support. Support can come in the form of friends, family, church or religious groups, online forums and communities, and one-on-one counseling. Choose the form of support that works best for you and is most compatible with your situation and personality.<sup>19</sup>

Although the cancer journey can feel lonely and isolated, you do not have to struggle with everything on your own. Reach out to your friends and family if they are willing to help.<sup>19</sup> If you are not sure about how to share your concerns, we have compiled some educational and supportive resources that may be helpful. Please see pages 14 and 18 of this guide for more information.

# Frequently Asked Questions

### What is ovarian cancer?

Ovarian cancer affects one or both ovaries, which are small round organs located on each side of the uterus. An ovary stores reproductive eggs, germ cells and produces the hormones estrogen and progesterone. 1,2

### How many women have ovarian cancer?

According to the Centers for Disease Control and Prevention, over 20,000 women in the United States develop ovarian cancer each year. Although it only accounts for 3 percent of all cancers that occur in women, ovarian cancer results in more deaths than any other cancer related to the female reproductive system. For women in the United States, ovarian cancer is the 10th most common cancer and fifth cause of cancer death behind lung and bronchus, breast, colorectal and pancreatic cancers.3

### How do I know if I am at risk for ovarian cancer?

The following risk factors may increase the risk of ovarian cancer:

- Older age (middle age or older)
- · Family history of ovarian cancer
- · Previous breast, uterine, or colorectal cancer
- Eastern European background
- Difficulty with pregnancy or never giving birth
- · Endometriosis (tissue from the uterus lining grows in other parts of the body)1
- Inherited gene mutations (BRCA 1 and 2)<sup>6</sup>

Even if you have one of more of these risk factors, you may not necessarily get ovarian cancer. However, it is best to be cautious and speak with your doctor and health care providers about your individual risk.1

### What are the symptoms of ovarian cancer?

Possible signs and symptoms of ovarian cancer to watch for 1,8:

- Pain or pressure in the area below your stomach and in between your hip bones (pelvic/abdominal area)
- · Back pain
- Bloating
- · Changes in appetite (feeling full too quickly or having difficulty with eating)
- Frequent urination and/or constipation

Signs and symptoms of ovarian cancer may be general and difficult to identify. It is important to notice if your symptoms are persistent and do not resolve after normal management with diet change, exercise, or rest. If you experience any of these signs and symptoms for longer than two weeks, contact your doctor.1

### What can I do to lower my risk of ovarian cancer?

Although there is no guaranteed method to prevent ovarian cancer, certain factors may reduce the risk of ovarian cancer<sup>1,7</sup>:

- · Birth control pills
- · Pregnancy and giving birth
- Gynecologic surgery: tubal ligation (tying your tubes), hysterectomy (surgically removing the uterus) and oophorectomy (removing ovaries)
- · Breastfeeding

### How is ovarian cancer detected?

For women who do not experience signs or symptoms, it may be difficult to diagnose ovarian cancer. Although there is no simple and reliable screening test specifically for detecting ovarian cancer, other tests may help with identifying ovarian cancer and can be offered by your doctor:1,8

- · Pelvic exam
- Transvaginal sonography
- CA-125 blood test, CA-125 is a protein produced by ovarian cancer cells

These tests may be useful for women with unexplained signs or symptoms of ovarian cancer, previous breast, uterine, or colorectal cancer or have a close relative with ovarian cancer.1

### How is ovarian cancer treated?

Potential treatment options for ovarian cancer include: 20,21

- Surgery
- Chemotherapy
- Targeted therapy
- Radiation
- Hormone therapy
- · Clinical trial

# Glossary of Important Terms

Bilateral salpingo-oophorectomy: Surgical removal of both ovaries and both fallopian tubes.

CA-125: A substance that may be found in high amounts in the blood of patients with certain types of cancer, including ovarian cancer.

**Chemotherapy:** Treatment that uses medications to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. Chemotherapy may be given by mouth, injection or infusion, or on the skin, depending on the type and stage of the cancer being treated. It may be given alone or with other treatments, such as surgery, radiation therapy, or biologic therapy.

Clinical trial: A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis or treatment of a disease.

Endometriosis: A condition in which endometrial (the layer of tissue that lines the uterus) tissue grows in abnormal places in the abdomen.

**Epithelial ovarian cancer:** Cancer that forms in the tissue covering the ovary. Most ovarian cancers are epithelial ovarian cancers.

**Debulking:** Surgical removal of as much of a tumor as possible. Debulking may increase the chance that chemotherapy or radiation therapy will kill all the tumor cells and may relieve symptoms.

Fallopian tubes: A slender tube through which eggs pass from an ovary to the uterus. In the female reproductive tract, there is one ovary and one fallopian tube on each side of the uterus.

**Germ cells:** A reproductive cell of the body. Germ cells become egg cells, or ova, in females and sperm cells in males.

**Gynecologic surgery:** Surgery related to the female reproductive tract (including the cervix, endometrium, fallopian tubes, ovaries, uterus and vagina).

**Gynecologic oncologist:** A doctor who has special training in diagnosing and treating cancers of the female reproductive organs.

**Hysterectomy:** Surgery to remove the uterus and sometimes the cervix. If the uterus and the cervix are removed, it is called a total hysterectomy. If only the uterus is removed, it is called a partial hysterectomy.

Hormones: One of many substances made by glands in the body. Hormones circulate in the bloodstream and control the actions of certain cells or organs.

**Oophorectomy:** Surgery to remove one or both ovaries.

Ovary: One of a pair of female glands in which the eggs form and the female hormones estrogen and progesterone are made. These hormones play an important role for breast development, body shape, body hair, menstrual cycle, fertility and pregnancy.

Pelvic Exam: A physical exam of the vagina, cervix, uterus, fallopian tubes, ovaries and rectum.

**Radiation therapy:** The use of high-energy radiation from X-rays, gamma rays, neutrons, protons and other sources to kill cancer cells and shrink tumors.

Staging: Performing exams and tests to learn the extent of the cancer within the body, especially whether the disease has spread from where it first formed to other parts of the body.

Stromal cells: A type of cell that makes up certain types of connective tissue

**Transvaginal sonography:** A procedure used to examine the vagina, uterus, fallopian tubes, ovaries and bladder. An instrument is inserted into the vagina that causes sound waves to bounce off organs inside the pelvis. These sound waves create echoes that are sent to a computer, which creates a picture called a sonogram.

**Tubal ligation:** An operation to tie the fallopian tubes closed. This procedure prevents pregnancy by blocking the passage of eggs from the ovaries to the uterus.

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# **Questions to Ask Your Physician**

A diagnosis of cancer can be overwhelming. Here are some questions you may want to ask your doctor or other health care professional, suggested by the American Cancer Society, Cancer Treatment Centers of America and the American Society of Clinical Oncology.<sup>23-25</sup> Take this list to your appointment. We've left room for notes and questions of your own.

What is ovarian cancer?
What causes ovarian cancer?
What are the symptoms of ovarian cancer?
What type of doctor should I see if I think I might have ovarian cancer?
What type of ovarian cancer do I have?
What is the stage and grade of my ovarian cancer?
What is my expected prognosis?

Has my cancer spread to other locations outside my ovaries?
What treatments do you recommend for me and why?
What are the goals of treatment? Is it to eliminate the cancer or to make me feel better?
How long will treatment take?
What side effects can I expect to feel from my treatment?
How will my sex life be affected by treatment? If so, for how long?
Will I be able to have children after my treatment?
Can my cancer still return even after treatment?

# Questions to Ask Your Physician (Continued)

How can I preserve my quality of life while undergoing treatment?		
What should I know about clinical trials?		
Where can I go for more information about clinical trials?		
What support services are available to me and my family?		
Should other women in my family be tested regularly for ovarian cancer?		
Are there any brochures or other printed material I can take home with me?		
With whom may I speak about my financial and insurance concerns?		

Questions of Your Own:	



200 Independence Ave., SW, Room 730E Washington, DC 20201

### **CONTACT INFO:**

Health helpline: 800-994-9662 Office inquiries phone: 202-690-7650

# Office on Women's Health

### womenshealth.gov

The Office on Women's Health (OWH) — within the U.S. Department of Health and Human Services – provides national leadership in advancing women's health through public policy, research, service delivery and education. The OWH develops, stimulates and coordinates women's health research, health care services, and public and health professional education and training across the agencies of the Department of Health and Human Services. The OWH developed womenshealth.gov, a website with over 800 topics on women's health, including reproductive health.

### Resource Checklist

- Information on ovarian cancer
- Printable fact sheets
- Additional resources



### ADDRESS:

14 Pennsylvania Plaza, Suite 2110 New York, NY 10122

1101 14th St. NW, Suite 850 Washington, DC 20005

### CONTACT INFO:

New York Office Phone: 212-268-1002 Washington, D.C. Office Phone: 866-399-6262

Email: info@ocrfa.org

# **Ovarian Cancer Research Fund Alliance**

### ocrfa.org

At Ovarian Cancer Research Fund Alliance, we work every day to fund cures, foster community, further conversations and, ultimately, the cause.

OCRFA is the largest global organization dedicated to fighting ovarian cancer. In addition to advancing research to prevent, treat and defeat ovarian cancer, OCRFA supports women and their families before, during and beyond diagnosis. The organization also works with all levels of government to ensure ovarian cancer is a priority.

- Information on ovarian cancer
- Information on clinical trials
- Community support program
- Research news
- Sponsored events



16057 Tampa Palms Blvd. W PMB #373 Tampa, FL 33647

### **CONTACT INFO:**

Phone: 866-288-7475 Email: info@facingourrisk.org

# **FORCE: Facing Our Risk of Cancer Empowered**

### Facingourrisk.org

FORCE is a nonprofit advocacy group with the mission of improving the lives of individuals and families affected by hereditary breast, ovarian, and related cancers. FORCE provides resources to determine risk factors for cancer and information about options for managing and living with risk factors, and support to individuals and families. It also aims to represent the concerns and interests of affected individuals and families to the cancer advocacy community, the scientific and medical community, the legislative community and the public.

### Resource checklist

- Information on ovarian cancer
- Clinical trial findings and enrollment opportunities
- Personalized guidance
- National helpline
- Advocacy resources



### ADDRESS:

PO Box 14066 Huntsville, AL 35815

### **CONTACT INFO:**

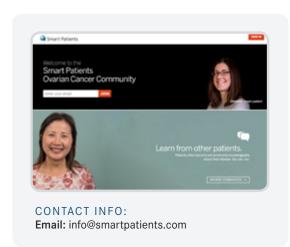
Email: info@liliesofthevalley.org

# **Lilies of the Valley**

### Liliesofthevalley.org

Lilies of the Valley is a nonprofit gynecologic cancer support and awareness group for individuals in Huntsville, Alabama, and the Tennessee Valley region. Its mission is to education, raise awareness, and disseminate information about gynecologic cancers to patients and survivors, the general public, and the medical community. In addition to monthly support groups and awareness events throughout the year, Lilies of the Valley also offers educational presentations called Teal Talks, as well as other resources and activities.

- Information about ovarian cancer
- Support groups
- **Educational presentations**



# SmartPatients.com

Smart Patients is an online community for patients and families affected by a variety of illnesses. Here you can learn at your own level about scientific developments related to your condition, share your questions and concerns with other members and use what you learn in the context of your own life. Subscribe to the site in general, or to the ovarian cancer discussion boards for patients and caregivers. Search for "ovarian" from Find Your Community, and enter your email.

### **Resource Checklist**

- Online support community
- Information on recent treatments
- Information on clinical trials
- Personal stories



### ADDRESS:

79 Main St., Suite 202 Framingham, MA 01702

### **CONTACT INFO:**

Phone: 508-655-5412

Toll Free: 866-920-OFTC (866-920-6382) Email: info@ovationsforthecure.org

# **Ovations for the Cure** of Cancer

### ovations for the cure.org

Ovations for the Cure, Inc. is dedicated to the relentless pursuit of a cure for ovarian cancer. Our education programs focus on increasing public awareness of the symptoms of ovarian cancer in an effort to improve earlier detection of ovarian cancer and thus better outcomes for women who have ovarian cancer. Secondly, our patient programs are created to give knowledge, hope and comfort to those women currently diagnosed and living with ovarian cancer. Ovations for the Cure, Inc. also provides critical funding for new and ongoing ovarian cancer research initiatives that focus on early detection, prevention, developing more effective treatments for ovarian cancer and curing ovarian cancer in our lifetime.

- Information on ovarian cancer
- Patient brochures
- Printable resources



165 West 46th St. Suite 712 New York, NY 10036

### CONTACT INFO:

Phone: 212-719-0364

Toll-Free: 844-ASK-SHARE (844-275-7427) Email: info@sharecancersupport.org

# **SHARE: Self-help for Women with Breast or Ovarian Cancer**

### sharecancersupport.org

SHARE helps those affected by breast or ovarian cancer to get the information and support they need to manage these diseases. SHARE empowers patients and survivors to work through their feelings and fears, carefully consider their options and take control of their health. All of SHARE's services are free of charge and provided by survivors who've been there.

### **Resource Checklist**

- Information on ovarian cancer
- National helpline
- Free webinars and online events
- Clinical trial matching service
- Patient support groups
- Resources for caregivers



### ADDRESS:

670 N. Clark St., Suite 2 Chicago, IL 60654

**CONTACT INFO:** 

Phone: 312-787-4412

# **Bright Pink**

### brightpink.org

Bright Pink is a national nonprofit organization that provides education and support to young women who are at high risk for breast and ovarian cancer. We arm young women with knowledge, options and a great attitude, and offer companionship and empathy during their journey. We empower them to take control of their breast and ovarian health and in turn, grant them the freedom and peace of mind to live a beautiful and fulfilling life.

- ✓ Peer-to-peer support programs
- Call to action
- Risk assessment tools
- ✓ Tips for a healthy lifestyle
- Materials for health care providers



1112 Montana Ave., Suite 861 Santa Monica, CA 90403

### CONTACT INFO:

Phone: 424-272-1749 Email: info@lcfocr.org

# **The Lynne Cohen Foundation**

### lynnecohenfoundation.org

Founded in 1998, the Lynne Cohen Foundation for Ovarian Cancer Research is a national nonprofit organization that raises funds to support and enable research and preventive care to improve survival rates for women with ovarian cancer by focusing on early detection and prevention. Through the Lynne Cohen Preventive Care Programs established at prestigious cancer centers across the country, women who may be at increased risk for cancer receive an individualized, comprehensive approach to cancer screening and prevention.

### **Resource Checklist**

- Information on ovarian cancer
- Personal stories
- Fundraising events



### ADDRESS:

3800 Maple Ave., Suite 435 Dallas, TX 75219

### **CONTACT INFO:**

Phone: 214-273-4200 Email: nocc@ovarian.com

# **National Ovarian Cancer Coalition**

### ovarian.org

The National Ovarian Cancer Coalition, Inc. (NOCC) is a 501(c)(3) charitable organization that provides education and awareness about ovation cancer through a toll-free help line, local NOCC chapters, comprehensive website, peer support, publications and awareness/education programs. Founded in 1995, the NOCC is a resource and women's health advocate.

- Information on ovarian cancer
- ✓ Information on awareness and risk assessment
- Local chapter events
- Additional resources
- News



421 Butler Farm Road Hampton, VA 23666

### **CONTACT INFO:**

Phone: 800-532-5274

Email: help@patientadvocate.org

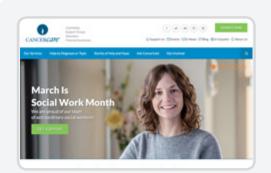
# **Patient Advocate Foundation**

### patientadvocate.org

The Patient Advocate Foundation is a national nonprofit organization that serves, through case managers, doctors and attorneys, as an active liaison between patients and their insurer, employers and/or creditors to resolve insurance, job retention and/or debt crisis due to their diagnosis. The group seeks to safeguard patients through effective mediation to ensure access to care, maintenance of employment and preservation of financial stability.

### **Resource Checklist:**

- ✓ Insurance and financial information
- Co-pay assistance
- Free webinars and information sessions



### ADDRESS:

275 Seventh Ave., 22nd Floor New York, NY 10001

### **CONTACT INFO:**

Phone: 888-813-HOPE (888-813-4637)

Email: info@cancercare.org

# Cancer Care

### cancercare.org

Cancer Care is dedicated to helping people face the many challenges of a cancer diagnosis. As the largest national nonprofit organization of its kind, Cancer Care provides free professional support services, including counseling, education, financial assistance and practical help to people across the country. Since its inception in 1944, Cancer Care has offered help and hope to more than two million people with cancer, their family members and friends, as well as health care professionals. Services are available to people of all ages, with all types of cancer and at any stage of the disease.

- Counseling with an oncology social worker
- Patient support groups
- Publications
- Personal stories
- Financial assistance programs

## **PATIENT EDUCATION RESOURCES**

Website	Address	Contact
Office on Women's Health womenshealth.gov	200 Independence Ave. SW Room 712E Washington, DC 20201	Health helpline: 800-994-9662 Office inquiries phone: 202-690-7650
Ovarian Cancer Research Fund Alliance ocrfa.org	14 Pennsylvania Plaza Suite 2110 New York, NY 10122	New York Office Phone: 212-268-1002
	1101 14th St. NW Suite 850	Washington, D.C. Office Phone: 866-399-6262
	Washington, DC 20005	Email: info@ocrfa.org
FORCE: Facing Our Risk of Cancer Empowered Facingourrisk.org	16057 Tampa Palms Blvd. W PMB #373 Tampa, FL 33647	Phone: 866-288-7475 Email: info@facingourrisk.org
<b>Lilies of the Valley</b> Liliesofthevalley.org	PO Box 14066 Huntsville, AL 35815	Email: info@liliesofthevalley.org
SmartPatients.com smartpatients.com/communities/ ovarian-cancer		Email: info@smartpatients.com
Ovations for the Cure of Cancer ovationsforthecure.org	79 Main St., Suite 202 Framingham, MA 01702	Phone: 508-655-5412 Toll Free: 866-920-0FTC (866-920-6382) Email: info@ovationsforthecure.org
SHARE: Self-help for Women with Breast or Ovarian Cancer sharecancersupport.org	165 West 46th St. Suite 712 New York, NY 10036	Phone: 212-719-0364 Toll-Free 844-ASK-SHARE (844-275-7427) Email: info@sharecancersupport.org
Bright Pink brightpink.org	670 N. Clark St., Suite 2 Chicago, IL 60654	Email: brightpink@bebrightpink.org Phone: 312-787-4412
The Lynne Cohen Foundation lynnecohenfoundation.org	1112 Montana Ave., Suite 861 Santa Monica, CA 90406	Phone: 424-272-1749 Email: info@lcfocr.org
National Ovarian Cancer Coalition ovarian.org	2501 Oak Lawn Ave., Suite 435 Dallas, TX 75219	Phone: 888-OVARIAN (888-682-7426) Email: nocc@ovarian.com

# FINANCIAL ASSISTANCE RESOURCES

Website	Address	Contact
Patient Advocate Foundation patientadvocate.org	421 Butler Farm Road Hampton, VA 23666	Phone: 800-532-5274 Email: help@patientadvocate.org
CancerCare cancercare.org	275 Seventh Ave., 22nd Floor New York, NY 10001	Phone: 888-813-4637 Email: info@cancercare.org

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# CUTE Connections®



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# curetoday.com

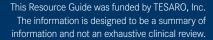
A patient video series brought to you by CUTE magazine, the premiere BPA-audited, direct-to-patient oncology publication.











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