



# FLASCO BRIEF

## Survivor Newsletter

### MAY 2020

**National Cancer Research Month**, observed each **May**, recognizes the importance of cancer research and the contributions of researchers, physician-scientists, survivors, and patient advocates across the United States who are dedicated to the conquest of cancer.

**National Cancer Research Month** is supported by Congress through special resolutions in the House and Senate.

**Cancer Research** has taught us about risk factors, environmental factors, health screenings, causes, treatment options, metastasis, recurrence, rates of survival, and even how healthy cells might be used to wipe out the cancerous cells. Cancer research is broad and reaches far beyond the study of the infected cells. The research helps us to understand cancer and the many aspects of it that will affect people who will be diagnosed with cancer, not to mention the millions already living with the disease. The years upon years of research devoted to cancer has led to valuable insight and life-saving measures. To emphasize the importance of the contributions of cancer research, the month of May was established as National Cancer Research Month and is led by the American Association for Cancer Research (AACR).



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## FROM THE EDITOR

**Have you visited the FLASCO Patient Portal website?**

**[www.patients.flasco.org](http://www.patients.flasco.org)**

FLASCO is continually working to improve and enhance this site to make it the one-stop resource for cancer warriors of Florida. We would love to hear your feedback and suggestions for ways to improve.

**[www.patients.flasco.org](http://www.patients.flasco.org)**

**Belong to an amazing support group?  
Please share with us!**

We would like to help spread the word about your supportive tribe and connect others with your group.

Please send information about your support group, or suggestions for the FLASCO Patient Portal Website to **[info@patients.org](mailto:info@patients.org)**

## MAY CANCER AWARENESS

Bladder Cancer Awareness Month

Brain Tumor Awareness Month

Melanoma and Skin Cancer Awareness Month

Skin Cancer Detection and Prevention Month

Cancer Research Month

# NAVIGATING CANCER

## Financial and Insurance

### Understanding the Costs Related to Cancer Care

A cancer diagnosis can be expensive, and many people have unplanned expenses related to their care. Often, finances are a source of stress and anxiety. Sometimes costs, keep people from completing cancer treatment. This increases health risks. It may also lead to more expenses in the future.

It is important to identify your potential medical and non-medical costs. This information will help you adjust your budget; and, it will allow you to seek financial assistance, if needed. Creating a financial plan helps reduce unnecessary clutter and stress. This allows you to focus on your health and wellbeing.

### **Factors that contribute to cost of cancer care**

Your personal costs will depend on several factors:

- \* The type of cancer treatment you receive
- \* The length of treatment
- \* The location of treatment
- \* Your health insurance coverage
- \* Whether you have supplemental insurance

Some costs might appear more obvious than others. For example, potential medication costs, based on insurance coverage. But you will also need to consider the hidden costs of cancer. Specifically, costs of daily living may increase with long-term illness and treatment. Along with increased expenses, you may need to work less. As a result, you could earn less money.

Talk about managing or lowering your care costs with members of your health care team, such as:

- \* Oncology Financial Counselors
- \* Oncology social workers
- \* Case Managers
- \* Oncology Nurses
- \* Your Doctor

These professionals can provide referrals to support services and financial resources. Consider talking with a representative from your doctor's office or your health insurance provider to learn more about your medical costs. Family members and friends can also help you manage finances.

For help with financial challenges, explore the services available through national and local organizations. And if finances cause significant stress, consider talking with a counselor.

### **Related Resources**

- \* [Questions to Ask About Cost](#)
- \* [Having the Cancer Cost Conversation: 5 Places to Start](#)
- \* [Health Insurance](#)
- \* [Cancer and the Affordable Care Act](#)
- \* [Cancer Is Expensive, Help Is Available](#)
- \* [Why You Should Speak Up About Struggling to Pay for Treatment](#)
- \* [Don't Let Money Prevent You From Being in a Clinical Trial](#)

## **Health Insurance** (Source: Cancer.Net – American Society of Clinical Oncology)

In the United States, insurance provides access to health care. Health insurance can help reduce the amount you need to pay for cancer care.

Most people get health insurance in 1 of 2 ways:

- \* Through an employer
- \* Through a government program. Government health insurance options include Medicare and Medicaid.

But some people do not receive health insurance at work. Others do not qualify for Medicare or Medicaid.

If this is your situation, visit [www.HealthCare.gov](http://www.HealthCare.gov). The website will outline options for purchasing health insurance. Or call 800-318-2596 (TTY: 855-889-4325).

These options are available because of the 2010 Patient Protection and Affordable Care Act (ACA). This law also changed U.S. health care insurance coverage rules.

[Additional information click here](#)

Download ASCO's free booklet, *Managing the Cost of Cancer Care*, as a printable PDF in [English](#) (32 pages) or in [Spanish](#) (36 pages).

For information about transitioning from job based coverage to other forms of coverage (including Medicaid and COBRA), see these resources: (Source: National Coalition for Cancer Survivorship)

- \* [Health coverage options if you are unemployed](#)
- \* [Losing Job-based Coverage](#)
- \* [Medicaid & CHIP coverage](#)
- \* [COBRA coverage and the Marketplace](#)
- \* [COBRA Continuation Coverage Questions and Answers](#)
- \* [Complex Case Scenarios - Preventing Gaps in Health Care Coverage Mini-Series: Transitioning from Employer-Sponsored Coverage to Other Health Coverage - June 5, 2015 \(slides\)](#)

For information on Special Enrollment Periods, see here:

- \* [Enroll in or change 2020 plans — only with a Special Enrollment Period](#)

For updated guidance on grace periods for binder and premium payments see here:

- \* [Payment and Grace Period Flexibilities Associated with the COVID-19 National Emergency](#)

## Mental and Emotional Well Being (Source: CancerCare)

### **May is Mental Health Awareness Month**

Mental health encompasses an individual's emotional, psychological and social well-being. These aspects of a person's well-being can be affected after a cancer diagnosis, during treatment and while in remission. It is important to remember that your health care team is there to treat the whole person, including your mental health concerns. Feelings like stress, anxiety and fatigue are common after a cancer diagnosis. Discussing these feelings with your health care team when they arise can strengthen your emotional well-being and provide an enormous sense of relief.

### **What mental health concerns can come up after a cancer diagnosis?**

Possible mental health concerns may include one or more of the following:

- \* Sadness is common after a cancer diagnosis. It is important to pay attention to intense bouts of sadness, as these can lead to depression.
- \* Anxiety (or worry) is a natural emotional experience but can intensify after a cancer diagnosis. Chronic anxiety can lead to depression or fatigue (extreme tiredness) over time.
- \* Fear is one of the many complex emotions that can arise after a cancer diagnosis. Fear of recurrence (the cancer returning) is also not at all uncommon for cancer survivors.
- \* Post-traumatic stress can be a response to a life changing event like a cancer diagnosis. Recently seeing a loved one go through a serious illness can also trigger personal trauma.

### **How can your health care team help?**

Providing your health care team with a thorough medical history (including any previous mental health diagnoses) will allow your team to provide better care. If any of the above referenced feelings arise, talk with your health care team about these feelings, and ask if they can refer you to a counselor. If necessary, your doctor may conduct a psychological evaluation. Keep in mind that treating the "whole person," also means treating one's emotions, so it is important for your health care team to know about any emotional distress. Whether you are seeing a social worker, psychologist, or psychiatrist, it is important that they communicate with the rest of your health care team. Lastly, make sure your oncologist knows if you are taking psychotropic medications.

### **How can someone living with cancer help themselves?**

**Take note of shifts in your mood, appetite or any changes that make it difficult to accomplish daily tasks.** Listen to loved ones if they notice changes in your mood. Sometimes they see changes that you might not recognize yourself. Speak to your health care team if these changes occur.

**Cognitive Behavioral Therapy (CBT).** This type of therapy can help you manage your feelings, challenge some of your negative thoughts and replace them with more helpful ones. To learn more about CBT, read the sheet titled, "[How to Recognize and Change Negative Thought Patterns When You Have Cancer.](#)"

**Try simple breathing exercises.** This four-step breathing exercise is one example that you can try:

- \* Take in a deep breath from your diaphragm (the muscle between your lungs and abdomen).
- \* Hold the breath for several seconds—however long is comfortable for you—and then exhale slowly.
- \* Repeat steps 1 and 2 two more times.
- \* Afterward, relax for a moment and let yourself feel the experience of being calm.

**Seek support.** Supportive resources like individual counseling help reduce emotional stress.

Below is a list of a few resources for additional information:

- \* CancerCare - Call 800-813-4673 to speak with one of CancerCare's oncology social workers and learn more about CancerCare's individual counseling and resources near you.
- \* *National Institute of Health (NIH)* - <https://www.cancer.gov/about-cancer/coping/feelings>
- \* *American Cancer Society (ACS)*– (<https://www.cancer.org/latest-news/nurture-your-emotional-health.html>)
- \* Centers for Disease Control (CDC)- <https://www.cdc.gov/cancer/survivors/caregivers/helping-cancer-survivors-stay-mentally-emotionally-healthy.htm>
- \* National Cancer Institute (NCI) - <https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-cancer-institute-nci>
- \* *National Coalition for Cancer Survivorship (NCCS)* - <https://www.canceradvocacy.org/>
- \* Patient Power - <https://patientpower.info/living-well/mental-and-emotional-well-being/>

## FDA UPDATES

### Latest Oncology Drug Approvals

#### **Advanced Epithelial Ovarian, Fallopian Tube, Or Primary Peritoneal Cancer**

The FDA approved niraparib (ZEJULA, GlaxoSmithKline) for the maintenance treatment of adult patients with advanced epithelial ovarian, fallopian tube, or primary peritoneal cancer who are in a complete or partial response to first-line platinum-based chemotherapy. [More Information](#). April 29, 2020

#### **Metastatic Triple-Negative Breast Cancer:**

The FDA granted accelerated approval to sacituzumab govitecan-hziy (TRODELVY, Immunomedics, Inc.) for adult patients with metastatic triple-negative breast cancer who received at least two prior therapies for metastatic disease. [More Information](#). April 22, 2020

## **CLL**

The FDA expanded the indication of ibrutinib (IMBRUVICA, Pharmacyclics LLC) to include its combination with rituximab for the initial treatment of adult patients with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL). [More Information](#). April 21, 2020.

## **Metastatic Cholangiocarcinoma**

The FDA granted accelerated approval to pemigatinib (PEMAZYRE, Incyte Corporation) for the treatment of adults with previously treated, unresectable locally advanced or metastatic cholangiocarcinoma with a fibroblast growth factor receptor 2 (FGFR2) fusion or other rearrangement as detected by an FDA-approved test. [More Information](#). April 20, 2020

## **Metastatic HER2-Positive Breast Cancer**

The FDA approved tucatinib (TUKYSA, Seattle Genetics, Inc.) in combination with trastuzumab and capecitabine, for adult patients with advanced unresectable or metastatic HER2-positive breast cancer, including patients with brain metastases, who have received one or more prior anti-HER2-based regimens in the metastatic setting. [More Information](#). April 17, 2020

## **Urothelial Cancer (LG-UTUC)**

The FDA approved mitomycin (JELMYTO™, UroGen Pharma) for adult patients with low-grade upper tract urothelial cancer (LG-UTUC). [More Information](#). April 15, 2020

## **Plexiform Neurofibromas**

The FDA approved selumetinib (KOSELUGO, AstraZeneca) for pediatric patients, 2 years of age and older, with neurofibromatosis type 1 (NF1) who have symptomatic, inoperable plexiform neurofibromas (PN). [More Information](#). April 10, 2020

## **Metastatic Colorectal Cancer**

The FDA approved encorafenib (BRAFTOVI, Array BioPharma Inc.) in combination with cetuximab for the treatment of adult patients with metastatic colorectal cancer (CRC) with a BRAF V600E mutation, detected by an FDA-approved test, after prior therapy. [More Information](#). April 8, 2020

## **Breast Cancer**

Merck Announces US Launch of ONTRUZANT® (trastuzumab-dttb), a Biosimilar of Herceptin® (trastuzumab). (Merck) Apr 15, 2020 – Merck has announced the U.S. launch of ONTRUZANT (trastuzumab-dttb), as a biosimilar of the reference biologic medicine Herceptin.

[read corporate press release](#)

## **Cervical Cancer**

Roche announced US Food and Drug Administration (FDA) approval for the cobas® HPV test for use on the fully automated, high-throughput cobas® 6800/8800 Systems.

[read corporate press release](#)

## **More FDA Information:**

✧ [FDA: Office of Hematology and Oncology Products](#)

✧ [FDA: Approved Drugs: Questions and Answers](#)

# SUPPORT GROUP HIGHLIGHTS

## AMERICAN BRAIN TUMOR ASSOCIATION

**A Message from Ralph DeVitto, President and CEO, National Brain Tumor Association, former CEO of the American Cancer Society, Florida Division, Inc.**



On behalf of the American Brain Tumor Association, I would like to wish my good friend and former colleague, Dorothy Green Phillips, former FLASCO Executive Director, a long, happy, and exciting retirement. She has earned it many times over.

May is Brain Tumor Awareness Month so we appreciate the opportunity to highlight the important work of the American Brain Tumor Association. Over 78,000 people will be diagnosed with a brain tumor this year and between 200,000 and 300,000 will be diagnosed with a metastatic brain tumor this year.

The ABTA offers an extensive array of services to patients and caregivers. We also collaborate with other organizations to ensure brain tumor patients receive the services they need. We help both newly diagnosed patients and those with recurring disease. We also fund breakthrough brain tumor research in the U.S. and around the world.

The COVID-19 pandemic has had a swift and devastating effect on our income so far this year. Your support is more important than ever. We have developed special webinars and information pages on our website to serve brain tumor patients and their families as they deal with their diagnosis in context of this pandemic. Please go to [ABTA.org](https://www.abta.org) for more information and to find out how you can help us advance our mission.

The American Brain Tumor Association is the nation's oldest nonprofit organization dedicated to brain tumor education, support, and research. Forty-five years ago, in 1973, the ABTA was founded by two mothers determined to find answers that, at the time, were not yet available. Since then, the ABTA has funded more than \$30 million in brain tumor research and now reaches a national audience, providing educational and support resources.

The ABTA is a steadfast advocate on behalf of the brain tumor community in the United States, and we are here to help patients, caregivers, and their loved ones as they navigate the brain tumor journey.

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[Learn More](#)  
[Watch Our Video](#)





## Bladder Cancer Advocacy Network



Bladder Cancer Advocacy Network was founded in 2005 and is the only national advocacy organization devoted to advancing bladder cancer research and supporting those impacted by the disease. BCAN is on the frontlines advocating for greater public awareness and increased funding for research to identify effective treatments and eventually, a cure for bladder cancer.

Each year, BCAN provides thousands of patients, caregivers and the medical community with the educational resources and support services they need to navigate their bladder cancer journey. BCAN works collaboratively with the medical and research professionals who are dedicated to the prevention, diagnosis and treatment of bladder cancer and empowers the patient community by allowing them to share experiences with others, and to participate in building awareness of the need for a cure. More Information: <https://bcan.org/>

## American Bladder Cancer Society



All services of the American Bladder Cancer Society are free of charge to everyone. The ABLCS is a 501(c)(3) non-profit organization and is supported by public donations. Our purpose is to offer support and information and to advocate for the bladder cancer community. We firmly believe that lives can be saved through awareness of bladder cancer's symptoms. Please consider helping us through your donation of time, talent, or treasure. Information on this site is not intended as medical advice but rather to help you formulate questions for your medical team. If you are having a true medical emergency, please seek immediate attention at a qualified care facility or from a medical professional. More Information: <https://bladdercancersupport.org/>

## Skin Cancer Foundation



Since 1979, The Skin Cancer Foundation has made tremendous strides in helping people understand the importance of skin cancer prevention, early detection and prompt, effective treatment. We could not do it without the collaboration and dedication of many talented individuals and entities. More Information: <https://www.skincancer.org/>

## Melanoma International Foundation



Our Vision: A future where top-notch melanoma treatment is accessible to all patients globally. Our Mission: To develop personalized strategies with patients so they may live longer, better lives. More Information: <https://melanomainternational.org/>

## Other Skin Cancer Support Groups and Organizations

- \* American Academy of Dermatology. For information and education on all types of skin cancers and melanomas. ... <https://www.aad.org/>
- \* American Cancer Society. ... [www.cancer.org](http://www.cancer.org)
- \* American Childhood Cancer Organization. ... [www.acco.org](http://www.acco.org)
- \* American Melanoma Foundation. ... <http://www.melanomafoundation.org/>
- \* CancerCare Inc. ... [www.cancercare.org](http://www.cancercare.org)

## FEATURED RESOURCES

### Resources for Patients - National Cancer Institute

[www.cancer.gov > resources-for > patients](http://www.cancer.gov/resources-for/patients)

Authoritative **information** about your type of **cancer**, as well as **information** on a wide range of **cancer** topics and the latest **cancer** research.

### NCCN Guidelines for Patients

<https://www.nccn.org/patients/guidelines/cancers.aspx>

NCCN Foundation<sup>®</sup> empowers you to make informed decisions at each step of your cancer journey. The NCCN Guidelines for Patients<sup>®</sup> and NCCN Quick Guide<sup>™</sup> sheets are based on the same treatment information your doctors use and help you talk to your doctor about the best treatment options for your disease.

*Florida Society of Clinical Oncology*

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