



# FLASCO BRIEF

## Survivor Newsletter

### SEPTEMBER 2020



**What Is Advocacy? (Source: NCCS)**  
*In cancer survivorship, advocacy is a continuum. It may begin at the personal level, but along the survivorship journey, self-advocacy efforts may broaden to include first group or organization advocacy, and later may move to public advocacy efforts.*



**TOOLS FOR YOUR ADVOCACY EFFORTS.**  
Check out the NCCS Advocacy Toolkit which further outlines what advocacy is, how a bill becomes a law, and provides several tools for advocacy with care planning legislation as an example of how to take part in advocacy. The toolkit has important tips for using media tools in advocacy efforts and for meeting and calling decision makers.

[Download the Advocacy Toolkit](#)

AARP Voting Information Link:  
<https://states.aarp.org/florida/election-voting-guide>

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# FROM THE EXECUTIVE DIRECTOR

*By Julie Newberry*



## Take Action!

Tell Congress to Expand Paid Leave for People With Chronic Health Conditions  
(Source: National Coalition on Cancer Survivorship)

We urge Congress to expand eligibility for the paid family and medical leave to include people with chronic conditions, like cancer, and working members of their households.

Because of their history of cancer and cancer treatment, cancer patients are especially vulnerable to COVID-19. Cancer survivors may be at higher risk of health complications from COVID-19 and may experience more serious infection if they acquire it.

Expanding eligibility for the paid family and medical leave program to include individuals the Centers for Disease Control (CDC) considers at high risk, will help ensure the health and safety of cancer patients and survivors.

NCCS is here to help. Use the links below to call or email your Members of Congress, or contact Lindsay Houff and we are happy to help you.

- [Find your Senators' emails and phone numbers](#)
- [Find your Representative's emails and phone numbers](#)
- [Find who your Members of Congress are using your zip code](#)

## Phone Script for Calling Congressional Offices

*Below is a brief script to use when calling Congressional offices to support paid leave.*

“My name is \_\_\_\_\_ and I am a constituent of yours from \_\_\_\_\_. I am calling to ask that you expand eligibility for the paid family and medical leave to include people with chronic conditions, like cancer, and working members of their households. This will help ensure that the health and well-being of cancer survivors like me (or my loved one), who are considered high risk for COVID-19, are protected and can remain home if their job would put their health at risk.”



For more tips on how to tell your story and relate them to talking points about expanding paid leave, download this helpful worksheet.

[Telling Your Story: Expanding Paid Leave Worksheet »](#)

# September Cancer Awareness

Childhood Cancer Awareness Month

Uterine Cancer Awareness Month

Gynecologic Cancer Awareness Month

Blood Cancer Awareness Month

Ovarian Cancer Awareness Month

Prostate Cancer Awareness Month

Thyroid Cancer Awareness Month



## NAVIGATING CANCER

### What to Say When Your Child Has Cancer (Source: Patient Power)

How can you help your child understand their own cancer diagnosis? As a child and adolescent therapist with a focus on trauma-informed care, expert Dr. Sierra Wait shares tips for families facing childhood cancer. Watch now and learn how to approach the conversation and maintain a sense of normalcy. [Learn More](#)

Learn more in the "Diagnosis" section of NCI's Children with Cancer: A Guide for Parents at [www.cancer.gov/parents-guide](http://www.cancer.gov/parents-guide).



### Taking Charge of Your Care (Source: Cancer.Net)

You can be a self-advocate by taking an active role in your cancer care.

This can be a positive experience that gives some people a sense of control in a time of uncertainty. Self-advocacy does not have to be time-consuming or difficult. It can be as easy as asking more questions at a doctor's appointment. It also does not mean that you alone are responsible for your cancer care. In fact, it commonly involves seeking additional support from others.

## **Being a self-advocate**

Self-advocacy is an ongoing process that begins at the time of a cancer diagnosis and continues through follow-up care after treatment. To *get started as a self-advocate*, consider these steps:

- Ask your health care team questions.
- Learn more about the type of cancer you have from your health care team or online. **Reliable websites** can provide:
  - Educational material
  - Programs and services
  - Support for people with cancer and their families

As always, discuss any information you find on the internet with your health care team.

- Ask about and take advantage of other services offered at your doctor's office, hospital, or clinic, including:
  - Counseling
  - Patient navigation services
  - Support groups
  - Nutritional counseling and fitness or movement classes. Talk with your doctor before you begin an exercise program.
- Connect with other people living with cancer and those who have had similar experiences. Some organizations have **support buddy programs** that pair cancer survivors with people who have been recently diagnosed.
- Feel confident about your choices. Consider seeking a **second opinion** about your diagnosis or treatment plan.
- Do not be afraid to ask for help managing nonmedical issues. These may include:
  - Cost of cancer care and health insurance
  - Transportation
  - Childcare

## **Tips on talking with your health care team**

Talking with your health care team about cancer may seem challenging. Some people feel that they are receiving too much information at once and are unable to understand everything they hear. Others feel that asking too many questions may seem disrespectful. But it is important to find the best way to ask for what you need and express your preferences and concerns. *Try using these strategies:*

- Keep a record to help you remember what you want to discuss with your doctor during your appointment.
- Prepare **a list of questions** for your doctor before your next appointment.
- During your appointment, take notes or record conversations. Or bring a friend or family member to help you take notes and keep track of the details. These methods will allow you to more accurately review the information after the appointment. Ask if there is any written information you can take home. This can be helpful for you to remember what you discussed in your appointment or to share with friends and family.

- Tell your doctor up front how much information you want. Some people like to know everything about the cancer, including statistics and chances for recovery. Others prefer to hear just enough information to help them make decisions about their treatment plan.
- Do not be afraid to speak up if the information you receive does not make sense. Your health care team wants to make sure that you fully understand the information they provide.
- Make sure you know the next steps in your care before leaving the doctor's office.

### **Finding additional help**

Sometimes, you may still have concerns after taking these steps. In such cases:

- Talk with a third party. This may include the head nurse or your family doctor. They may be willing to discuss the matter with your cancer health care team or offer helpful suggestions.
- If you are having a problem with a doctor or another member of your health care team while in the hospital, speak with a **social worker** or a hospital patient service representative.
- If your doctor's communication style does not match yours or you want a different approach for your care, consider finding a new doctor or health care team. Ask for references from friends, family members, and other people with the same type of cancer. And call your insurance company to find out whether the new doctor is part of your plan's network. Also, make sure to ask how much extra it would cost to see the doctor if he or she is not in your health care network. Learn more about **choosing a doctor** and **finding a treatment center**.

## LIVING WELL



### **How to Rekindle Intimacy After Cancer Treatment (Source: Patient Power)**

Expert tips, tools and tricks to help you reboot your post-cancer body and rekindle intimacy after cancer treatment. [Learn More](#)

### **Cancer and Your Self-Image: Adjusting is an Ongoing Process (Source: Cure)**

A cancer diagnosis can cause stark transitions in self-image, sense of self and identity, as both the illness and treatment can significantly alter a person's body.

As cancer treatment begins, a person's body may begin to look and feel different, which can impact self-image and sense of self. Treatments can also bring physical scars, hair loss, weight changes, loss of limbs or organs, the need for an ostomy, reduced fertility or other changes, all of which impact a person's physical relationship with their body and have lasting social and emotional impacts.


## **Cancer Alters Sense of Self**

Because sense of self plays a significant role in how we interact with the world and relate to others, people who experience physical changes as a result of cancer may not feel comfortable doing things they wouldn't have given a second thought to before, such as meeting new people or going out in public. For those who've experienced physical changes, it's important to talk about these feelings, understand that they're normal and recognize that it takes time to emotionally adjust to the new physical realities.

Managing emotional concerns related to self-image is an ongoing process. People with cancer must acknowledge what happened to them and how it affects their day to day. This requires navigating a sense of emotional and physical loss and confronting how they see themselves — and how they think the world may see them too.

As an example, a breast cancer survivor, said, "It doesn't matter the age, just the idea that you are removing your entire breast. I lost everything. ... You don't feel beautiful." The cancer survivor later related living with physical changes like hair loss to playing a role as an actress: "I'm saying to myself, 'This is a part, and I'm playing this part until I finish chemo. I am beautiful in my own way.'"

## **Finding support and Strength After Cancer**

 Because physical changes can be reminders of the disease and its treatments, they can be difficult to reconcile with how someone previously viewed themselves. Individual counseling can help survivors process the uniquely personal impact of cancer and transition to a new physical reality by offering a safe, supportive and uncensored environment to express thoughts and feelings.

Oncology social workers, counselors, therapists or supportive professionals may be able to share strategies for practicing mindfulness, self-care and kindness amidst this emotionally turbulent experience. Additionally, joining a support group — and connecting with people facing similar challenges — can also help lessen feelings of loneliness and isolation. As much as friends and family want to understand, they often can't relate. Support groups are a place where survivors can express their fears, feelings and experiences with other people who truly understand because they're living with cancer, too.

Although physical changes can serve as reminders of negative and painful memories, they can also be symbols of strength.

A survivor said "when you are pale yellow and your skin is totally different, it's harder to feel beautiful; however, cancer helped me realize that it's all about the heart. I feel beautiful in a different way. It's not the outside beauty. The beauty is inside us — and now I'm a strong believer of this."

# FDA UPDATES

## Latest Oncology Drug Approvals

### LYMPHOMA

- tafasitamab-cxix (MONJUVI, MorphoSys US Inc.). July 31, 2020: [More Information](#)
- belantamab mafodotin-blmf (Blenrep, GlaxoSmithKline). August 5, 2020: [More Information](#)

### METASTATIC MELANOMA

- atezolizumab (Tecentriq, Genentech, Inc.) July 30, 2020:FDA Summary : [More Information](#)

### MULTIPLE MYELOMA

- carfilzomib (KYPROLIS, Onyx Pharmaceuticals, Inc.) and daratumumab (DARZALEX, Janssen Biotech, Inc.). August 20, 2020: [More Information](#)
- belantamab mafodotin-blmf (Blenrep, GlaxoSmithKline). August 5, 2020: [More Information](#)

### **More FDA Information:**

- \* [FDA: Office of Hematology and Oncology Products](#)
- \* [FDA: Approved Drugs: Questions and Answers](#)

## SUPPORT GROUP HIGHLIGHTS

### **Patient Advocate Foundation (PAF)**



Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses. <https://www.patientadvocate.org/>

The National Patient Advocate Foundation (NPAF) is the advocacy affiliate of the Patient Advocate Foundation. They are dedicated to improving health care access, quality and affordability through policies, programs and practices that optimize the experience and outcomes for patients and caregivers. They bring the patient voice to the forefront by articulating powerful individual stories and the collective needs of the community. <https://www.npaf.org/>

The Co-Pay Relief Program may help with all therapeutic and supportive medications, including generic or bioequivalent products prescribed to treat and/or manage the patient's disease or condition. The program helps patients on a first-come, first-serve basis and processes applicants in the order in which their completed applications are received.

To apply for assistance please visit <https://copays.org/portal/#/login>, with access available for patients, providers and pharmacies, or connect with our team via phone at 866-512-3861.

# FEATURED RESOURCES

## What Legal and Financial Protections do Cancer Survivors Have During a Pandemic?

(Source: NCCS)

Monica Fawzy Bryant, Esq. and Joanna Fawzy Morales, Esq. are two cancer rights attorneys (and sisters) who saw the need to help individuals diagnosed with cancer, caregivers, advocates, and health care professionals, navigate the plethora of legal and practical issues that arise after a diagnosis — so they founded Triage Cancer.



NCCS speaks with them about how cancer survivors can receive resources and education on legal issues needed during the COVID-19 pandemic and beyond.

[Listen to the Episode »](#)

[Access COVID-19 and Cancer Resources »](#)

- **National Prostate Cancer Awareness Month (ZERO — The End of Prostate Cancer)**
  - See Cancer Health’s Prostate Cancer Basics page and news and information about prostate cancer. Learn more about the prostate cancer community from the Prostate Cancer Foundation, Zero and the Prostate Cancer Research Institute.
  - Prostate Cancer: Patient Empowerment Network - <https://powerfulpatients.org/help-by-cancer-diagnosis/prostate-cancer/>
- **Childhood Cancer Awareness Month (American Childhood Cancer Organization)**
  - See Cancer Health’s news and information about childhood cancer. Learn more about the childhood cancer community from the Children’s Cancer Research Fund and individual cancer organizations such as the Leukemia & Lymphoma Society and the Pediatric Brain Tumor Foundation.
- **Ovarian Cancer Awareness Month (National Ovarian Cancer Coalition)**
  - See Cancer Health’s Ovarian Cancer Basics and Breast Cancer Basics pages, and news and information about ovarian cancer and BRCA breast cancer. Find out more about the ovarian cancer community and the hereditary breast and ovarian cancer community from FORCE and the Ovarian Cancer Research Alliance.
- **Blood Cancer Awareness Month (The Leukemia & Lymphoma Society)**
  - Leukemia, lymphoma, multiple myeloma and myeloproliferative neoplasms are all cancers that affect blood cells. See Cancer Health’s Blood Cancers Basics, Leukemia Basics, Lymphoma Basics, and Multiple Myeloma Basics pages, and news and information about blood cancers, leukemia, lymphoma and multiple myeloma. Learn more about the blood cancer community from the Leukemia & Lymphoma Society, the Lymphoma Coalition and the International Myeloma Foundation



- **Gynecologic Cancer Awareness Month ([Foundation for Women's Cancer](#))**
  - There are five main types of gynecological cancer, affecting the cervix, ovaries, uterus, vagina, and vulva. Cervical Cancer Awareness Month is observed in January, while September is also Ovarian Cancer Awareness Month. Cervical cancer is the fourth most common cancer in women. See Cancer Health's [Cervical Cancer Basics](#), [Ovarian Cancer Basics](#), and [Uterine and Endometrial Cancer Basics](#) pages, and news and information about [cervical cancer](#), [ovarian cancer](#), [uterine cancer](#), [vaginal cancer](#) and [vulvar cancer](#). Learn more about the gynecologic cancer community from the [Foundation for Women's Cancer](#), which is part of the Society of Gynecologic
  
- **Thyroid Cancer Awareness Month**
  - Cure: <https://www.curetoday.com/articles/thyroid-cancer-awareness-month-what-you-need-to-know>
  - [Thyroid Cancer | American Thyroid Association](#)
  - [ThyCa: Thyroid Cancer Survivors' Association, Inc.](#)
  - [Light of Life Foundation](#)
  - [Thyroid Cancer - American Cancer Society](#)
  - [Thyroid Cancer, Information, Resources - CancerCare](#)
  - [Thyroid Cancer | Cancer Support Community](#)
  - [Thyroid Cancer—Patient Version - National Cancer Institute](#)