

ANNUAL REPORT 2023

# NATIONAL COALITION FOR CANCER SURVIVORSHIP

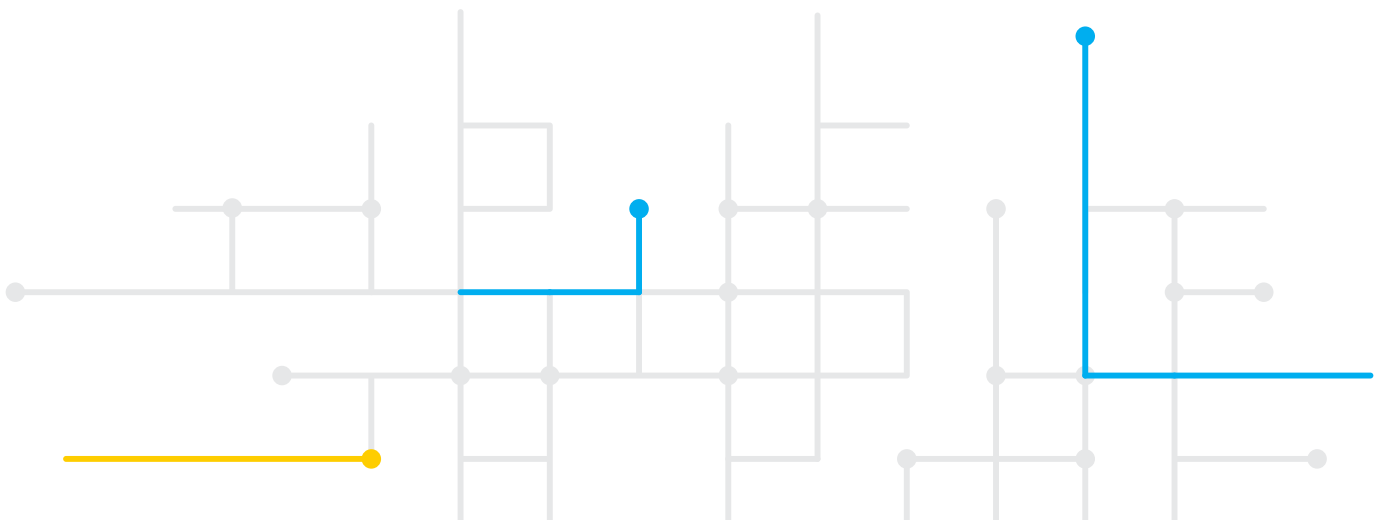


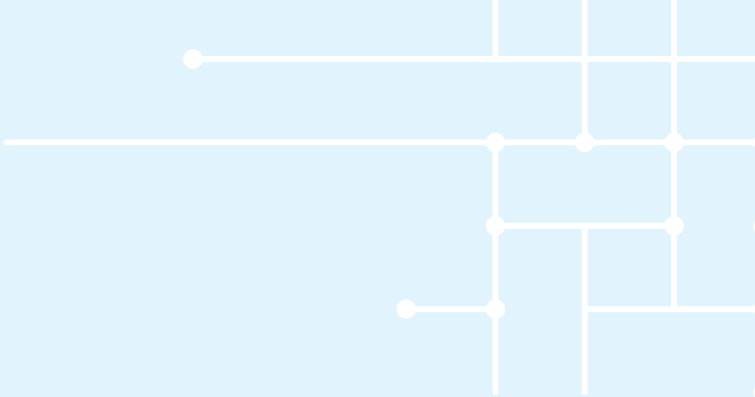
NATIONAL COALITION  
FOR CANCER SURVIVORSHIP

'23


# TABLE OF CONTENTS

LETTER FROM CEO	4-5
THE STATE OF SURVIVORSHIP	6-11
ADVANCING POLICY	12-15
CANCER POLICY ROUNDTABLE	16-17
CANCER POLICY AND ADVOCACY TEAM (CPAT) SYMPOSIA	18-21
EMPOWERING ADVOCATES	22
SURVIVORSHIP CHAMPIONS	23
ELEVATING SURVIVORSHIP	24-25
STORIES OF SURVIVORSHIP	26-27
ELLEN L. STOVALL AWARDS	28-29
NCCS IN THE NEWS	30-31
DONOR SPOTLIGHT	32-33
DONOR LIST	34-35
NCCS LEADERSHIP AND STAFF	36-37





Our mission is  
to advocate for  
**quality cancer**  
**care** for all  
people touched  
by cancer.



“

We empower survivors and advance policy to transform health care for all people touched by cancer.



Dear Friends,

As we reflect on another successful year, I am thrilled to share the advancements in cancer policy and advocacy NCCS achieved in 2023. This year has been nothing short of remarkable, demonstrating our unwavering commitment to championing cancer survivors and their loved ones.

This year, NCCS played an instrumental role in advocating for access to DIEP flap breast reconstruction, an important option for individuals in need of reconstruction. We convinced the Centers for Medicare and Medicaid Services (CMS) to retain the DIEP Flap codes, securing continued access to the procedure. This triumph is a testament to the power of collaborative advocacy and our dedication to ensuring that patients have access to the most comprehensive and effective treatment options. The significance of this achievement extends beyond policy; it directly impacts the lives of those navigating breast reconstruction options.

In 2023, NCCS convened two sessions of the Cancer Policy Roundtable, delving into crucial topics in cancer survivorship and policy. In the Spring session, we discussed access to high quality cancer care, patient navigation, and the FDA's accelerated pathways approval process. In the Fall, we discussed the Inflation Reduction Act, Medicare Advantage Plans, and centering patient-reported outcomes in clinical trials and clinical practice. These meetings brought together a diverse array of stakeholders, fostering a collaborative environment for insights, meaningful dialogue, and progress. I encourage you to explore the details of these sessions on our website to gain a deeper understanding of the presentations and conversations that took place.

Our annual State of Survivorship Survey provided continued insight and understanding of the experiences and challenges faced by cancer survivors. This year, we added a companion survey for caregivers, further illuminating the opinions of those touched by cancer. The insights and data gathered from this survey play a pivotal role in shaping our work, guiding our policy initiatives, and enhancing our communication with policymakers. For a comprehensive overview of this year's survey findings, I invite you to explore the detailed report available on our website.

In closing, I extend my heartfelt gratitude to each of you for your steadfast support of NCCS and our mission. Your contributions, whether through time, resources, or advocacy, are indispensable to the success of our mission. Without your support, none of this would be possible, and we look forward to continued collaboration in the years ahead.

Sincerely,



**Shelley Fulda Nasso, MPP | Chief Executive Officer**

# BETTER CARE FOR A BETTER LIFE

Our mission is to advocate for quality cancer care for all touched by cancer. We represent the more than 18.1 million Americans who share the survivorship experience of living with, through, and beyond a cancer diagnosis.

2023 was a remarkable year in many ways, most notably, that the Centers for Medicare and Medicaid Services (CMS) announced that it will retain procedure codes for breast cancer reconstruction, after hearing feedback from NCCS and other patient advocates, patients, and health care professionals.

We convened stakeholders from across the cancer community at our spring and fall Cancer Policy Roundtable events, hosted another cohort of Elevate Ambassadors for in-person training, and brought together survivors and caregivers to advocate for critical cancer survivorship policy.

Additionally, we worked to address the inequities highlighted in our 2023 State of Cancer Survivorship Survey, which showed that younger, Hispanic/Latino, female, and low-income patients face disparities that cause them to experience poorer care and a lower quality of life than other cancer survivors.

Our Cancer Policy and Advocacy Team, Elevating Survivorship and Survivorship Champions programs grew in 2023, emphasizing the increasing demand for effective advocacy in the cancer community. NCCS continues to be a trusted voice for advocacy and policy, ensuring access to quality cancer care for all who are touched by cancer.

## **YOUR SUPPORT NEVER WAVERED. IT ALLOWED US TO:**

- + Provide invaluable resources to cancer survivors, connecting them with top experts and other survivors who could answer their questions;
- + Expand our resources to help cancer patients and providers navigate a new environment in cancer care;
- + Advocate for policies to protect cancer survivors and enhance their quality of life.

# STATE OF SURVIVORSHIP

## SURVEY: 2023



NATIONAL COALITION  
FOR CANCER SURVIVORSHIP

# AMPLIFYING SURVIVORS' VOICES

The 2023 State of Survivorship Survey explores the cancer patient and survivor journey from a range of perspectives to better understand how NCCS can support our mission to advocate for quality care for all.

New this year, we included a companion survey of caregivers to determine how caregivers align with and differ from patients regarding decision-making and satisfaction with care. We also inquired about experiences working with cancer, survivors' interest in prescription drug monthly payment plans, advertising for cancer treatments, and survivors' experiences with integrative care.

The research, conducted in partnership with Edge Research in the spring of 2023, helps NCCS build on and track findings from previous years. Survey respondents represent a wide range of stages of diagnosis, demographics, socioeconomic levels, and available support systems, using quotas to make sure the sample was representative of cancer patients nationally by age, gender, race, ethnicity, and region (based on data from the American Cancer Society and National Cancer Institute).

In addition to surveying a nationally representative sample, we also survey survivors who are connected to NCCS. As we have found in past years, NCCS-connected respondents had higher expectations in their assessments of quality care, were more empowered and engaged in decision-making about their care, and were better able to find a range of support systems.

The 2023 State of Survivorship Survey demonstrates that when patients receive coordinated and quality care from their health care team, have excellent support, and have financial resources or assistance to alleviate worry about medical costs, they are more likely to have positive experiences and outcomes.



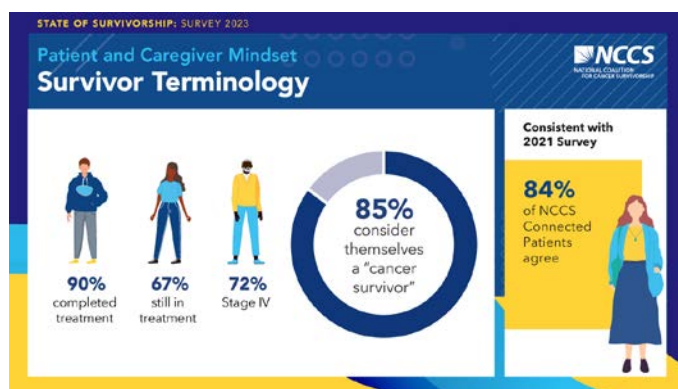
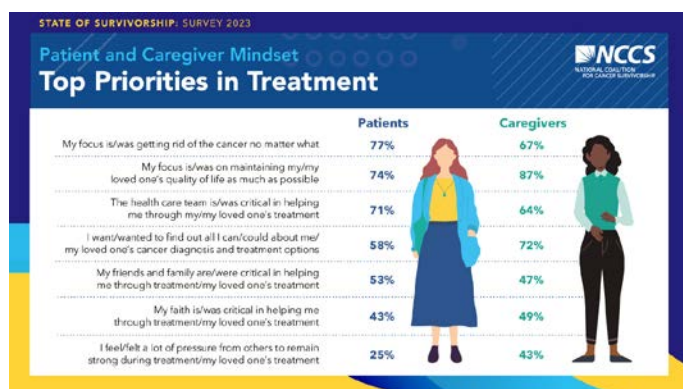
As established in survey results in previous years, majorities of patients express a high degree of satisfaction with their cancer journey. This year, respondents indicated increased satisfaction with screening and risk assessment, treatment decision-making, and overall treatment and care.

Patients and caregivers continue to report financial hardship. While the number of patients who were impacted financially decreased slightly nationally, respondents who identified as young, Black, Hispanic, Stage IV, or less educated reported more financial hardship.

Our 2023 State of Cancer Survivorship shows us where there are gaps in care and support, resulting in unequal outcomes for cancer survivors. Our work has never been more urgent.

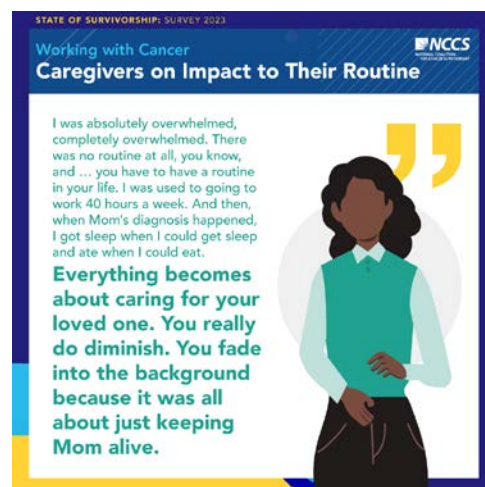
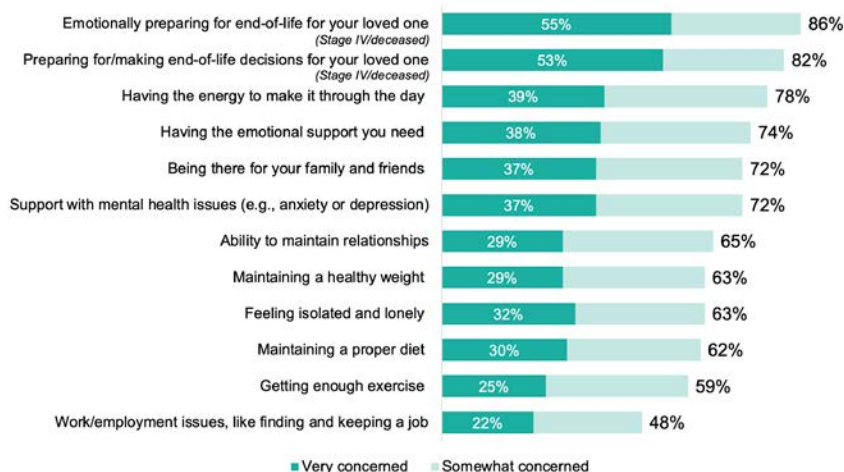
## PATIENT & CAREGIVER MINDSET

Patient reliance on their doctor to make treatment decisions has increased again this year, with over half reporting that they relied on their doctor to choose the best course of action. Caregivers, however, report being more proactive than patients, with a large majority saying they wanted to learn everything they could about their loved one’s diagnosis and treatment options.



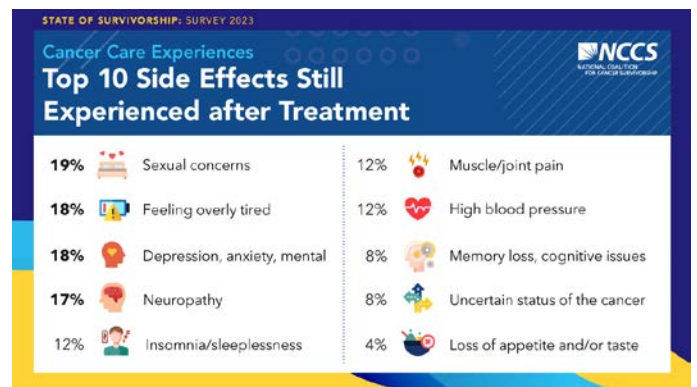
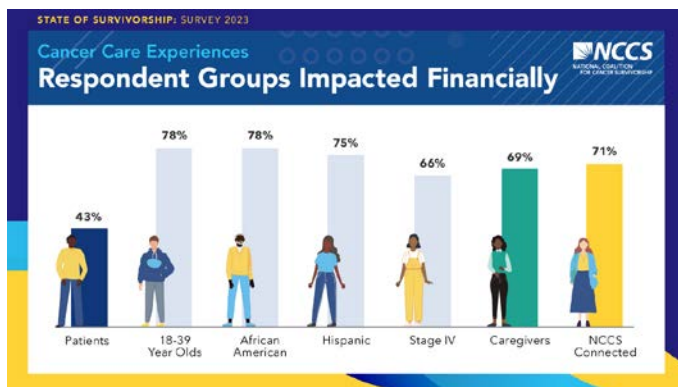
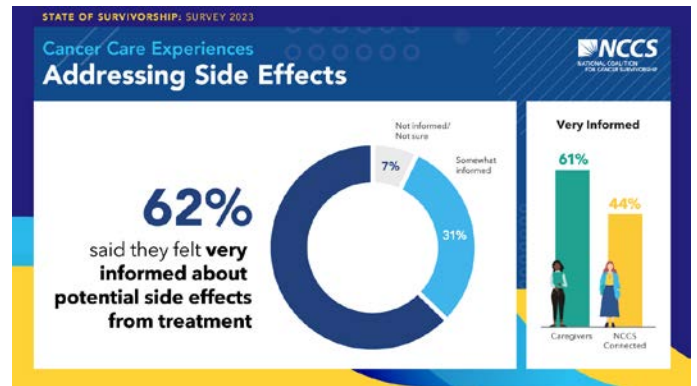
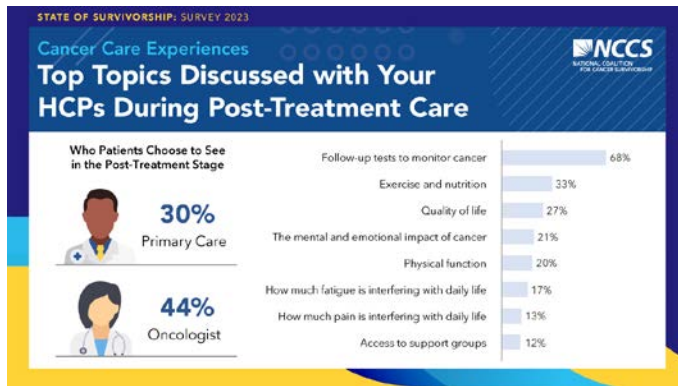
## CAREGIVERS' EXPERIENCES

Majorities of caregivers report grappling with a variety of physical, emotional, and mental health issues of their own. Most notably, 86% of caregivers were at least somewhat concerned with emotionally preparing for their loved one’s death. At least three-fourths of caregivers shared concerns about end-of-life decision-making, having enough energy to make it through the day, and getting the emotional support they need.



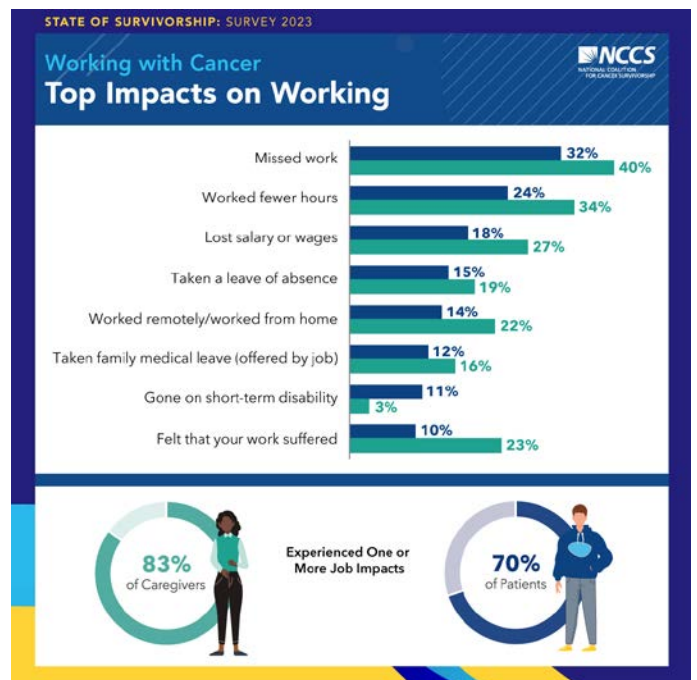
## CARE EXPERIENCES

Care Experiences. Most patients remain satisfied with each phase of their care and their health care team. Caregivers are more critical than patients, as their satisfaction with care is at least 10 points lower at nearly every phase of the cancer journey and related to assessments of the care team.



## WORKING WITH CANCER

Many patients and caregivers who worked during cancer treatment experienced issues, most commonly missing work, working fewer hours, and loss of salary or wages. Most say their productivity was impacted, though this is more profound among caregivers, who were more likely to say they were stressed and distracted at their job. Many patients reported wanting to continue working during this time because it helped take their mind off their cancer.



## INTEGRATIVE ONCOLOGY

Six-in-ten patients report receiving some form of integrative care during their cancer journey, particularly women, younger patients, Black and Hispanic patients, and those connected to NCCS. General well-being and mental health were the key drivers to integrative oncology. The most common types of integrative modalities were prayer and spiritual practices, exercise, and dietary supplements.

### Reasons for Using Integrative Care Services/Therapies

General wellbeing	62%
Coping with emotional, mental impact of cancer	44%
Giving me a sense of control over my illness	37%
Providing hope	33%
Managing symptoms, side effects of treatment	31%
Managing symptoms, side effects of cancer	30%
Preventing cancer recurrence	25%
Suggested by people I trust	20%
Treating my cancer	18%

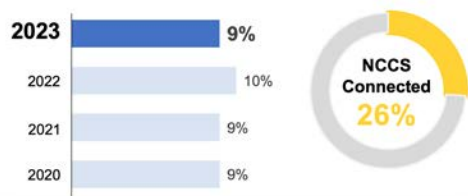
### Reasons for NOT Using Integrative Care Services/Therapies

Was not aware these therapies existed	31%
Not covered by my health insurance	12%
Concerned @ lack of evidence on safety, efficacy	9%
Not supported by my healthcare team	7%
Too expensive	7%
Concerned about potential side effects	2%
Concerned @ interactions w. cancer treatment	2%
My healthcare team recommended against using	1%
Not sure	26%

## CLINICAL TRIALS

Participation in clinical trials is on-par with previous years at 9%.

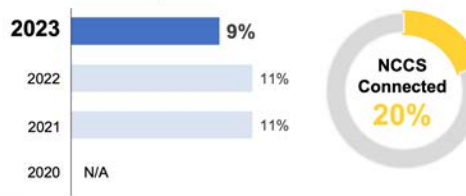
### Did you participate in a clinical trial related to your cancer diagnosis?



#### Higher among:

- 19% Younger (18-39)
- 18% Hispanic
- 16% Palliative Care
- 19% Immunotherapy
- 15% Biomarker Testing
- 15% Genetic Counseling
- 14% Targeted Drug Therapy
- 14% Chemo
- 13% Still In Treatment

### Did your health care team offer/discuss a clinical trial with you?

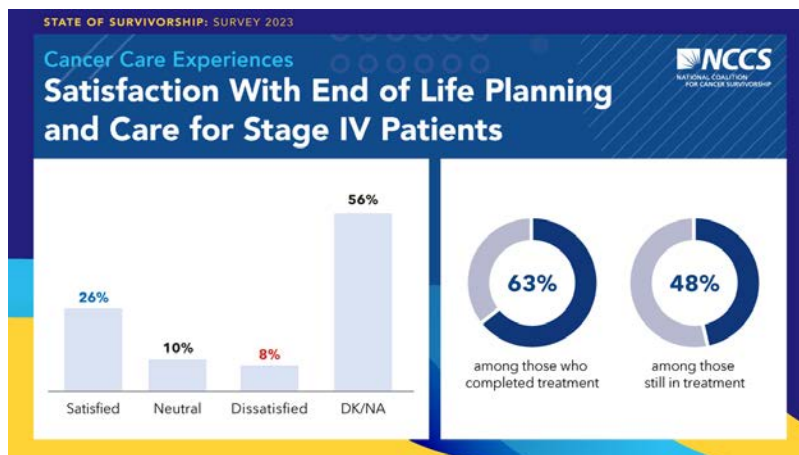


#### Higher among:

- 25% Younger (18-39)
- 29% Black
- 25% Hispanic
- 22% Palliative Care
- 21% Still In Treatment
- 20% Immunotherapy
- 18% Biomarker Testing
- 18% Targeted Drug Therapy
- 17% Urban
- 16% Genetic Counseling
- 16% Chemo

## END-OF-LIFE PLANNING AND CARE

The majority of patients with Stage IV cancer who were asked about their satisfaction with end-of-life planning and care were unable to comment, which may indicate that they have not had these conversations as part of their care.



# ADVANCING POLICY

In 2023, NCCS focused on access to care, health equity, and advocating for quality cancer care for survivors and their caregivers. Our policy priorities included:

## COMPREHENSIVE CANCER SURVIVORSHIP ACT

Representatives Debbie Wasserman Schultz (D-FL), Brian Fitzpatrick (R-PA), and Mark DeSaulnier (D-CA), and Senators Amy Klobuchar (D-MN) and Ben Cardin (D-MD) introduced H.R. 4363 and S. 2213, the Comprehensive Cancer Survivorship Act (CCSA), comprehensive bipartisan legislation intended to improve survivorship care. This legislation addresses the entire continuum of care—from diagnosis to active treatment and post-treatment—to improve survivorship, treatment, and transition for all survivors.

The cancer journey does not end once active treatment ends, and survivors need lifelong support for their disease. To improve their quality of life and health outcomes, cancer survivors need resources to help monitor for secondary cancers and late and long-term effects caused by their cancer treatment. Additionally, health care providers need resources to provide appropriate care for survivors throughout the entire continuum of care. The CCSA addresses existing gaps in survivorship care and aims to improve quality of care and navigation of health care systems for survivors, their loved ones, and their health care providers.

### **This comprehensive legislation will:**

- + Provide coverage for care planning services;
- + Develop navigation services for survivorship;
- + Establish employment assistance grants for survivors, caregivers, and their families;
- + Provide education and awareness through resources for survivors and health care providers;
- + Ensure coverage for fertility preservation services, and;
- + Require a study of the existing reimbursement landscape and development of an alternative payment model for survivorship care.



## CANCER CARE PLANNING AND COMMUNICATIONS ACT

Congressman Mark DeSaulnier (D-CA), a cancer survivor, reintroduced H.R. 5183, the Cancer Care Planning and Communications Act (CCPCA), legislation to establish a Medicare service for cancer care planning.

Cancer care planning has been identified as an element of quality cancer care for all Americans. The National Academy of Medicine, medical professional societies, and cancer patients have embraced the idea that all patients should receive a treatment plan from the cancer care team.

- **Benefit to patients:**

Provides information patients need to make treatment decisions, coordinate their care, and effectively transition from active treatment to survivorship.

- **Benefit to providers:**

Helps ensure the patient is receiving the right care at the right time, care is coordinated, and resources are used effectively.

- **Benefit to the health care system:**

Ensures appropriate and effective use of cancer care resources and encourages delivery of high-quality, coordinated care.

Many cancer patients still do not receive a written plan explaining their diagnosis, prognosis, treatments, and expected symptoms, leaving them to navigate the complexities of a cancer diagnosis without clear direction or knowing what to expect from their care.

Coordinated cancer care outlined in a written care plan—care that integrates active treatment and symptom management—improves patient outcomes, increases patient satisfaction, and reduces utilization of health care resources.



## ACCESS TO DIEP FLAP BREAST RECONSTRUCTION

In January 2021, the Centers for Medicare and Medicaid Services (CMS) announced the sunsetting of code S2068 for DIEP flap breast reconstruction and the use of CPT® code 19364 for autologous flap breast reconstruction procedures. NCCS actively advocated against this decision in an effort to protect access to DIEP flap procedures. DIEP flap is an important reconstruction option for individuals who choose reconstruction with their own tissue, rather than breast implants. The plan to eliminate certain breast reconstruction codes created barriers to care for cancer survivors seeking access to medically appropriate breast reconstruction.

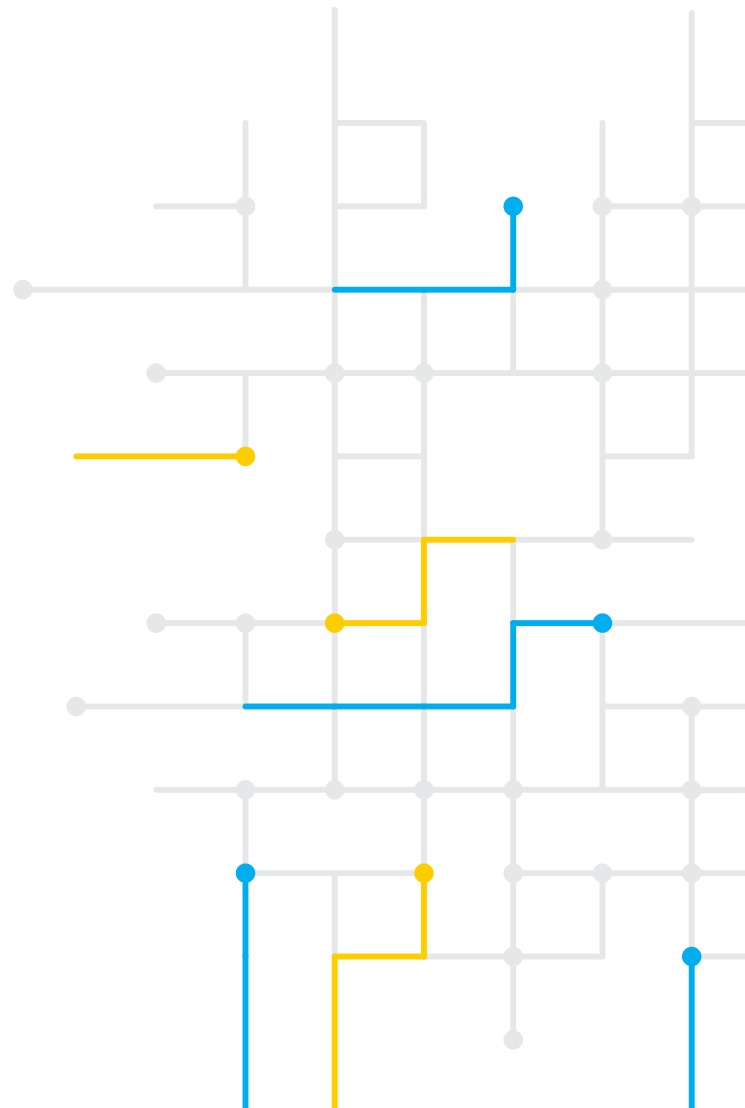
NCCS partnered with other patient advocacy organizations and the Community Breast Reconstruction Alliance, led by microsurgeon Dr. Elisabeth Potter, to alert CMS to the access challenges that resulted from the plan to eliminate the codes.

- In the spring, NCCS drafted a letter to CMS, which was signed by 34 patient advocacy organizations, 12 medical professional societies, and 231 health care professionals, including hospitals, practices, and individual health care providers. NCCS also included a petition with more than 4,600 signatures.
- In May, NCCS and the Community Breast Reconstruction Alliance met with CMS leadership to detail concerns about access to care.
- On June 1, CMS hosted a public meeting, in which they sought input on its decision to sunset the S code. NCCS CEO Shelley Fuld Nasso spoke at the public meeting and urged CMS to retain the codes.
- In June, STAT News published an op-ed by NCCS Board Vice Chair Lisa D. T. Rice on the threat to access of DIEP flap breast reconstruction surgery.

In August, CMS announced that it would retain procedure codes for breast cancer reconstruction, after receiving feedback from NCCS and other patient advocates, patients, and health care professionals.

## ACCESS TO AFFORDABLE INSURANCE

NCCS remains a committed member of the Partnership to Protect Coverage, a diverse coalition of patient and caregiver organizations advocating for millions of people living with serious, acute, and chronic health conditions to ensure health care is affordable, accessible, adequate, and understandable for all. Prior to the Affordable Care Act (ACA), cancer survivors were at the mercy of the health care system, often forced to pay exorbitant premiums or were simply denied coverage altogether. Today, America's 18.1 million cancer survivors benefit from the ACA's patient protections that provide them with quality, affordable, and accessible health care coverage. Through the ACA, cancer patients and survivors can now purchase insurance through Healthcare.gov and state insurance exchanges. The ACA has afforded protections related to out-of-pocket expenses, lifetime caps, and pre-existing conditions. The Partnership to Protect Coverage members collaborate to advocate for continued access to the ACA's insurance protections.



## MEDICAID EXPANSION

NCCS works on policy efforts to address health equity and reduce disparities in outcomes. The problem of health equity is complex, as some of the factors that lead to inequity are deeply rooted in social determinants of health and systemic and institutional barriers. Many policies that would improve access to care would contribute to reducing disparities.

According to researchers from the American Cancer Society, a quarter of the approximately 600,000 annual cancer deaths in the United States could be prevented if everyone had access to the same prevention, screening, and treatment. The ACA, including its expansion of Medicaid, has reduced disparities in access to care and mortality rates, compared to states that chose not to expand Medicaid. Medical debt is also lower in Medicaid expansion states. NCCS advocates for access to Medicaid, both through the ACA and through pandemic policies and flexibilities that allowed individuals to retain Medicaid coverage during the public health emergency.

## POWER OF PARTNERSHIPS

NCCS is proud to be part of several coalitions that advocate for policies that improve cancer care and survivorship. In 2023, these partnerships included:

- **Cancer Leadership Council:**  
A patient-centered forum of cancer patient organizations, professional societies, and research organizations addressing public policy issues in cancer.
- **Comprehensive Cancer Control National Partnership:**  
A collaborative group of diverse national organizations working together to build and strengthen comprehensive cancer control efforts across the country.
- **National Navigation Roundtable:**  
A national coalition of 80 member organizations to advance navigation efforts that eliminate barriers to quality care, reduce disparities, and foster ongoing health equity across the cancer continuum.
- **Partnership to Protect Coverage:**  
A diverse coalition of patient and caregiver organizations advocating on behalf of millions of patients and consumers living with serious, acute, and chronic health conditions to ensure health care is affordable, accessible, adequate, and understandable for all.
- **Patients and Caregivers for Paid Leave:**  
A national coalition of patient advocacy organizations and partners advocating for paid family and medical leave for people living with and/or caring for individuals who have a serious illness or health condition.
- **Tobacco Control Partners Coalition:**  
A national coalition of diverse stakeholders advocating for tobacco control policies to protect Americans from tobacco products and reduce tobacco-related diseases like cancer.



# ENGAGING WITH POLICYMAKERS AND LEADERSHIP

For the past 23 years, NCCS has convened leading stakeholders in the cancer community at the semi-annual Cancer Policy Roundtable (CPR). Participants discuss pressing issues related to cancer research, developing new cancer therapies, and delivering quality cancer care.

## CANCER POLICY ROUNDTABLE — SPRING 2023

NCCS brought together experts and cancer survivors to discuss a number of pressing issues impacting cancer survivorship and quality cancer care. Clinicians, patient advocates, and policy experts, as well as speakers from the U.S. Food and Drug Administration, Centers for Medicare and Medicaid Services, and National Cancer Institute (NCI), discussed important topics, such as patient navigation, implementation of the Inflation Reduction Act prescription drug provisions, and the accelerated approval pathway for cancer drugs. Additionally, Dr. Otis Brawley, Bloomberg Distinguished Professor at Johns Hopkins University and NCCS board member, delivered a presentation on the future of quality cancer control, including how we can provide high-quality care to populations that often do not receive it. Ellen Lukens from the Center for Medicare and Medicaid Innovation (CMMI) shared the vision and future of CMMI, including next steps for their upcoming projects. Finally, Dr. Emily Tonorezos from NCI's Office of Cancer Survivorship (OCS) highlighted the important work of OCS and the challenges of delivering quality cancer survivorship care.



NCCS CPAT members attend Spring Cancer Policy Roundtable.



Shelley Fuld Nasso, NCCS CEO, Bonny Morris, PhD, MSPH, RN from American Cancer Society, Kashyap Patel, MD from Carolina Blood and Cancer Care, Robert Winn, MD from VCU Massey Cancer Center, and CPAT member Sharon Rivera Sanchez from Trials of Color and Saving Pennies 4 a Cure discussed how patient navigation services can improve access to quality cancer care and explored the challenges associated with delivering these services.

Ellen Lukens, Deputy Director of the Center for Medicare and Medicaid Innovation (CMMI), delivered the afternoon keynote during which she shared the vision and future of CMMI.



## CANCER POLICY ROUNDTABLE — FALL 2023

NCCS convened another successful Cancer Policy Roundtable, hosting a compelling series of panels and guest speakers and discussing critical issues in cancer survivorship care. Esteemed speakers from the Johns Hopkins School of Medicine and Bloomberg School of Public Health, Centers for Medicare and Medicaid Services, KFF, and the Brookings Institution, as well as clinicians, patient advocates, and policy experts, participated in the panels. Topics included implementation of the Inflation Reduction Act and the potential impacts on innovation, the benefits and trade-offs of Medicare Advantage plans, and the impact of ongoing chemotherapy drug shortages on cancer patients and providers. In an interview with cancer survivor and author Katrece Nolen, Katrece shared the “survivor perspective,” recounting her lived experience and lessons learned as a 10-year Inflammatory Breast Cancer Survivor. Additionally, Dr. Claire Snyder from Johns Hopkins School of Medicine explained her work leading the PROTEUS Consortium and stressed the importance of patient-centered research and practice.



Dr. Claire Snyder, a pioneer in patient-centered outcomes research, delivered the keynote address titled “Patient-Centered Research and Practice: The PROTEUS Consortium.”



Chad Ramsey, MPA of Ovarian Cancer Research Alliance, Ryan Spencer, MD of Univ. of Wisconsin School of Medicine and Public Health, Kalah Auchincloss, JD, MPH of Greenleaf Health, and Marta E. Wosińska, PhD of The Brookings Institute engaged in a lively discussion about the impact of ongoing chemotherapy drug shortages on cancer patients and providers.

# RISING TO THE OCCASION FOR ADVOCATES

NCCS' Cancer Policy and Advocacy Team (CPAT) is our premier program that engages cancer survivors, caregivers, and health care professionals who advocate for quality cancer care.

The CPAT program currently engages nearly **1,100 cancer advocates**, including survivors and caregivers, and welcomed **158 new members** to CPAT in 2023.



NCCS board member Lisa D. T. Rice accompanies advocates and CUPID students to Capitol Hill to advocate for quality cancer care.



Kevin Oeffinger, MD, Founding Director of the Duke Cancer Institute (DCI) Center for Onco-Primary Care delivered the keynote address, "How Patients Can Partner with Primary Care to Improve Survivorship."



## IN-PERSON SYMPOSIUM

The 2023 CPAT Symposium celebrated our 10th annual event with nearly 100 participants, including advocates, caregivers, and medical students from the CUPID (Cancer in the Under Privileged Indigent or Disadvantaged) Program at Johns Hopkins, Indiana, and Ohio State Universities. NCCS has invited rising second-year medical students in the CUPID program to the CPAT Symposium every year since 2016, an important collaboration that benefits both advocates and students alike.

The CPAT Symposium is an opportunity to network with other advocates, develop advocacy skills, and learn about cancer policy issues. Attendees developed an in-depth understanding of survivorship legislation and visit Capitol Hill to share your story with legislators and advocate for the legislation. They learned about topics including cancer rehabilitation, mental health, communication, and the National Cancer Institute's Office of Cancer Survivorship. During the three-day event, attendees had the opportunity to learn, share their experiences and support each other. They left Washington, DC empowered to advocate for themselves and improve survivorship care in their communities.



Medical students from the CUPID (Cancer in the Under Privileged Indigent or Disadvantaged) Program at Johns Hopkins, Indiana, and Ohio State Universities gather at the CPAT Symposium.

This year, NCCS supported advocates with a wide range of expert-led sessions, panels, and workshops:

- **Mapping Your Story:** Point Park University Director of the Center of Media Innovation Andrew Conte, PhD shared the step-by-step process of cultivating a story for an intended audience by creating an introductory hook, sharing two to three important details, revealing a dramatic turn, and leaving your audience with a takeaway that they will remember.



NCCS CEO Shelley Fuld Nasso accompanies CPAT members to Capitol Hill to share their perspectives on quality cancer care with policy makers.

- **Hill Day Preparation:**

Shelley Fuld Nasso, NCCS CEO and Haley Smoot, NCCS Director of Public Policy gave an overview of the Comprehensive Cancer Survivorship Act, prepared advocates to weave their story into discussion of the legislation, and provided guidance on how to engage with legislative staffers and members of Congress in meetings on Capitol Hill.

- **Advocate Panel:**

*Building Relationships with Policymakers:* CPAT Members Loretta Herring, Louis Lanza, Jr. and Sandra Finestone, PsyD participated in a panel moderated by NCCS Vice Board Chair Lisa D. T. Rice to share their experience about building lasting relationships with legislators when they return home after the CPAT Symposium.

- **Fireside Chat:**

*Generational Impact in the Cancer Community:* CPAT Members Heidi and Catie Floyd joined Shelley Fuld Nasso, NCCS CEO to discuss how this mother/daughter team become actively engaged in legislative advocacy.

- **Improving Doctor Patient Communication:**

Kevin Oeffinger, MD from Duke University School of Medicine, and CPAT Steering Committee Member Desiree Walker discussed what is needed to achieve successful patient communication, including maintaining eye contact, sharing honesty about the realities of cancer care and communicating with the entire family. CUPID Alumni Noah Davis and Ryan Hannon joined the conversation to share what they had learned the previous year with new medical students in attendance and emphasized the need for their peers to recognize the importance of treating the “whole” patient instead of just focusing on the cancer treatment.

- **Get Loud:**

*The Power of Cancer Rehabilitation and Why it Matters:* ReVital Cancer Rehabilitation Senior Director of Research and Clinical Development Mackenzi Pergolotti, PhD, OTR/L and ReVital Cancer Rehabilitation Program Director Hilary Hinrichs, PT, DPT, CLT, WCS shared the vital role of cancer rehabilitation in improving the quality of life for cancer survivors.

- **Cancer Hope Network:**

*Walking Your Path with You:* Cancer Hope Network CEO Beth A. Blakey and Director of Programs Samantha Schrage shared how the organization supports cancer survivors and caregivers by creating meaningful connections through peer-to-peer support to replace fear with hope. Cancer Hope Network Volunteer Cancer Survivor Mentor Claudio Pannunzio explained the importance of resilience and courage in providing support to fellow cancer survivors, and Volunteer Caregiver Mentor Gregory D. Blake M.S. Ed, LRIC shared the importance of caregivers to participate in self-care and other tips to navigate the health care system.



CPAT members engage with presenters at CPAT Symposium.





- **Keynote:**

*How Patients Can Partner with Primary Care to Improve Survivorship:* Founding Director of the Duke Cancer Institute (DCI) Center for Onco-Primary Care Kevin Oeffinger, MD presented best practices for cancer survivors to receive survivorship care in the primary care setting.

- **Introducing the National Cancer Institute (NCI) Office of Cancer Survivorship (OCS):**

OCS Deputy Director Michelle Mollica, PhD, MPH, RN, OCN presented the history, purpose and current research opportunities that are presently being funded. CPAT Steering Committee Bethany Ross shared how her advocacy supported the research being conducted on understanding and addressing the survivorship needs for people living with advanced and metastatic cancers.

## HILL DAY

On June 22, 2023, CPAT members spent the day on Capitol Hill supporting the Comprehensive Cancer Survivorship Act (CCSA). Before advocates headed to Capitol Hill to advocate for this important legislation, Representative Debbie Wasserman Schultz (D-FL-25) and Senator Amy Klobuchar (D-MN), co-leads of the CCSA, addressed advocates and shared their motivation for pursuing the legislation. Representative Wasserman Schultz acknowledged the challenging work that lies ahead and called on all members of the cancer community to lend their voices to this collective effort. NCCS successfully secured 114 scheduled meetings with congressional offices in both the House and Senate, with more than 80 advocates from 27 states participating. In these meetings, NCCS advocates met with their members of Congress and congressional staff members and urged their support for the CCSA.



Senator Warnock and CPAT members advocate for quality cancer care on Capitol Hill.



Representative Brian Fitzpatrick and CPAT members advocate for quality cancer care on Capitol Hill.

## VIRTUAL SYMPOSIUM

In September 2023, we hosted a Virtual CPAT Symposium for CPAT members to continue their advocacy training. Health policy expert Debra Curtis joined NCCS CEO Shelley Fuld Nasso for a “fireside chat” to discuss the most recent developments in Congress and health policy in Washington. The Elevating Survivorship Cohort from 2022 explained how they implement health equity and build community survivorship programs in their communities. In his keynote address, Richard L. Deming, MD, founder of Above+Beyond Cancer, talked about the need to find hope in cancer survivorship. Dr. Deming shared stories of some of his patients, detailing both their healing journeys and their literal journey together to Mount Everest. Finally, Sidney Kushner, Founder and Executive Director of Connecting Champions, hosted a workshop on the art of career networking. He highlighted how to identify and connect with professionals to activate your network.

# EMPOWERING ADVOCATES

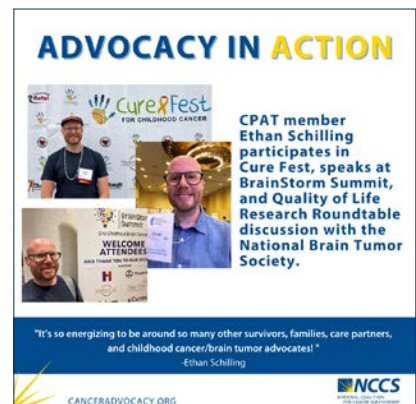
As members of CPAT, advocates affect change in the cancer community by engaging in opportunities at the local and national levels. In 2023:

## NCCS CPAT Members also supported various panels and interviews, including:

- + NCI Survivorship Guideline Committee
- + NCI Informatics Technology for Cancer Research Conference
- + NCI Telehealth Research Centers of Excellence Conference
- + Society of Integrative Oncology Conference
- + 3rd Annual Gynecologic Cancer Research-Survivor Summit
- + Society of Immunotherapy of Cancer Annual Meeting
- + Interview with BreastCancer.org - Beyond Treatment: Expecting More from your Follow-Up Care
- + Interview with NPR - 'We're not doing that': A Black couple won't crowd fund to pay medical debt
- + CPAT Webinar: Media Advocacy
- + Academy of Oncology Nurse & Patient Navigators Annual Conference
- + American Congress of Rehabilitation Medicine Annual Conference
- + Indiana University's Virtual Cancer Advocacy Panel
- + The Leukemia and Lymphoma Society's Podcast

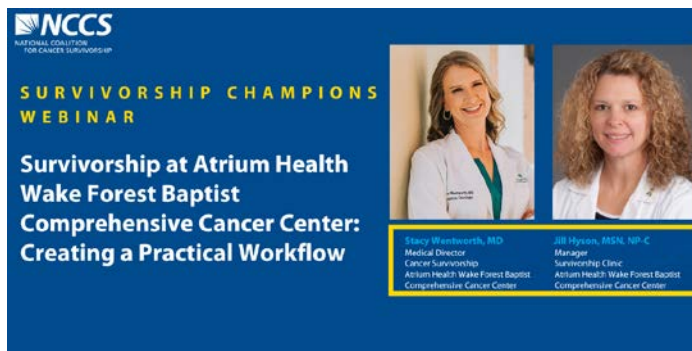
## We nominated CPAT Members for important roles within the following programs:

- + DoD Breast Cancer Research Program
- + DoD Cancer Research Program
- + SCIENTIST > SURVIVOR PROGRAM®
- + ASTRO Patient Guidelines Committee
- + Latino Cancer Patient Advocates Training
- + University of Maryland Research Study
- + NCI Office of Advocacy Relations
- + PCORI Advisory Panel



# SURVIVORSHIP CHAMPIONS

The Survivorship Champions Program is a community for researchers and clinicians, with a multi-directional information exchange about best practices, lessons learned, and effective models of survivorship care.



NCCS gives Survivorship Champions members the opportunity to share their best practices and expertise with the cancer community through our webinar series.

The first webinar focused on survivorship care implementation. *“Survivorship at Atrium Health Wake Forest Baptist Comprehensive Cancer Center: Creating a Practical Workflow”* presented by Stacy Wentworth, MD, and Jill Hyson, MSN, NP-C, who discussed survivorship care as a critical component of a patient’s cancer journey. They shared the patient and provider workflow, best practices for managing moderate and severe distress, and referrals and orders.

The second webinar discussed the American Society for Clinical Oncology’s (ASCO) Guidelines for Exercise, Nutrition, and Weight Management and how to best implement them in a clinical setting. Sami Mansfield, founder of Cancer Wellness for Life, and Wendy Demark-Wahnefried, PhD, RD, a professor of nutrition sciences at the University of Alabama at Birmingham led the discussion, presenting strategies for health care professionals to improve wellness for patients with a history of cancer.

Survivorship Champions offers a platform for clinicians and researchers to share their best practices and expertise within the cancer community through engaging webinars. These sessions serve as a vital resource for health care professionals, providing valuable insights and strategies to enhance survivorship care.

# ELEVATING SURVIVORSHIP

The Elevating Survivorship Program empowers advocates and survivorship professionals who work to improve survivorship care in their communities.

NCCS provides training, support, and networking opportunities to help Ambassadors develop and execute a plan of action for their project. Ambassadors work to refine their projects during a two-day training, and are supported throughout their term through collaborative webinars, 1:1 mentoring, and more.

In August 2023, NCCS brought together ten Elevate Ambassadors from communities across the country for two exciting days of training and workshops in Arlington, VA.

- **Arti Patel Varanasi, PhD, MPC, CPH**, of Advancing Synergy and 2022 Elevate Ambassador led a discussion on defining health equity in cancer care and addressing closing gaps and eliminating disparities.
- **Mary McCabe, RN, MA**, retired director of Memorial Sloan Kettering's Cancer Survivorship Program, shared how to collaborate with hospital systems.
- **Susan Leigh, RN**, retired oncology nurse and founding member of NCCS, recounted the history of the survivorship movement and the evolution of advocacy.
- **Veronika Panagiotou, PhD and Kara Kenan** provided guidance on implementing a program design and marketing plan.

At the conclusion of training, Ambassadors were prepared to return to their communities with a course of action for carrying out their survivorship projects.





# Meet the 2023 Elevating Survivorship Ambassadors:



**MONIQUE WILSON, LEESBURG, GA**

Elevate Project: Local survivorship program, offering practical and emotional support to ease the transition from treatment to survivorship through workshops, retreats, and seminars.



**PATRICIA RIFFENBURGH, VENTURA, CA**

Elevate Project: Local comprehensive survivorship program, offering educational information and workshops on nutrition, exercise, mindfulness, and more.



**ELIZABETH OWENS, LEXINGTON, NC**

Elevate Project: Develop additional support and awareness focused on the thyroid cancer community in the Winston-Salem, NC area.



**ERICA MENEFEE, MS, BSN, RN, CPT, CES, BHCN, DESOTO, TX**

Elevate Project: Breast cancer navigation toolkit for the AYA community and providers.



**YVONNE MCLEAN FLORENCE, DREXEL HILL, PA**

Elevate Project: Develop mini-survivorship resource corners (MSRC) in community churches.



**TAMRON LITTLE, ORANGE PARK, FL**

Elevate Project: Create a community hub dedicated to helping women cancer survivors navigate their survivorship journey.



**LOUIS LANZA, JR., TURNERSVILLE, NJ**

Elevate Project: Restart men's support group for Greater Philadelphia area.



**GIANNA DEROCHE, FULLERTON, CA**

Elevate Project: Develop a seminar that addresses important topics for patients transitioning out of active treatment.



**LAURIE CHRISTENSEN, VANCOUVER, WA**

Elevate Project: Develop an in-depth educational series about sexual health after cancer treatment for survivors, care team members, and oncology staff.



**ANDREA ANAMPA-GUZMÁN, BUFFALO, NY**

Elevate Project: Develop targeted initiatives to provide evidence-based information and resources for health care professionals interested in survivorship care.

# STORIES OF SURVIVORSHIP AND ADVOCACY



## WOODY BROKENBURR

Woody Brokenburr, a cancer survivor since the age of 9, has dedicated his life to advocacy, driven by the challenges he faced from his osteosarcoma diagnosis and the disparities in cancer care he's witnessed throughout his life. His advocacy mission stems from personal gratitude and a desire to ensure access to quality cancer care for all, particularly underserved communities.

Woody actively engages in diverse advocacy roles, serving as the Vice President of Community Conscience for the City of Thousand Oaks, CA, and contributing to programs like the Fielding School of Public Health at UCLA's Minority Training Program in Cancer Control Research. He has been a patient advocate at the Los Robles Medical Center, served on the Scientific Advisory Committee at the American Cancer

Society, and contributed to Stand Up to Cancer's Translational Lung Cancer Research collaborative. Woody is also Chair Emeritus of the Greater Conejo Valley Chamber of Commerce, actively writing about cancer survivorship and equity in publications like Onco'Zine, Survivorship Today, and CURE Magazine.

Through NCCS, Woody has found a powerful platform to amplify his efforts. As a Cancer Policy and Advocacy Team (CPAT) member, Woody has gained access to valuable resources and a supportive community, enabling him to advocate more effectively for cancer patients. As an Elevate Ambassador in 2020, Woody's collaboration with NCCS on the Power of Pink Symposium showcased their joint commitment to addressing health disparities and improving access to breast cancer care. Woody Brokenburr's advocacy experiences highlight the crucial role of advocates as agents of change and champions for quality cancer care.

"NCCS provides so many opportunities to educate oneself in the latest research outcomes and advocacy opportunities to help yourself and others as we embark upon our cancer journey. It's important to get involved so that we can make sure that more of us survive a cancer diagnosis, get diagnosed early on to ensure a favorable outcome, and also to foster empathy for people living with metastatic cancer."



## MARY GLEN

Mary Glen, an Army officer diagnosed with cancer while deployed to South Korea in 2020, has transformed her cancer journey into a powerful advocacy mission. Motivated by the lack of care and communication she received during her diagnosis and treatment, Mary is on a mission to be a voice for others, especially soldiers facing health challenges. Her advocacy is rooted in empowering individuals to share their stories, find strength, and embrace joy on their cancer journeys.

Diagnosed with Papillary Thyroid Carcinoma, Mary Glen serves as a powerful voice on social media, particularly Instagram (@TheNotSoGoodCancer), creating a community where individuals openly share experiences and support each other. Core to Mary's advocacy is the belief that every survivor's story is valuable.

According to Mary, NCCS has been instrumental in amplifying her advocacy efforts. Attending the CPAT Symposium was transformative, shifting her perspective on the value of her story in encouraging and supporting others. NCCS has empowered Mary to be a voice for fellow survivors, spread awareness, and enhance advocacy within the cancer community.

Reflecting on her first CPAT Symposium experience, Mary says:

“This experience was truly monumental. It taught me that every survivor's story is valuable and that it's essential to share those stories to encourage and support others.”



Woody Brokenburr at the UCLA Minority Training Program in Cancer Research.



Mary Glen recording a video interview at the CPAT Symposium.



# AWARDING INNOVATIVE ACTION

The Ellen L. Stovall Award for Innovation in Patient-Centered Care is given annually to individuals or organizations whose commitment to innovations in patient-centered cancer care helps deliver better outcomes and a higher quality of life for those living with and beyond cancer.

NCCS created the Stovall Award in honor of Ellen Stovall, our longtime CEO, who passed away in 2016 due to cardiac complications from her cancer treatment. In 2023, NCCS presented the 8th annual Stovall Award to Phuong Gallagher and Mary McCabe, RN, MA.



Mary McCabe RN, MA and Phuong Gallagher



**PHUONG GALLAGHER**  
**RECIPIENT OF THE PATIENT ADVOCATE AWARD**

Phuong Gallagher is a leading national advocate, collaborating with doctors, advocacy and support organizations, and researchers to promote awareness, self-advocacy, and research. She focuses on outreach to and education of adolescent and young adult (AYA) patients, empowering them to become knowledgeable self-advocates, while also facilitating improved communication between doctors, researchers, and the larger patient community.



**MARY MCCABE RN, MA**  
**RECIPIENT OF THE HEALTH CARE PROVIDER AWARD**

Mary McCabe, RN, MA has garnered multiple national awards for her work in cancer survivorship. She is currently a consultant in Cancer Survivorship and Medical Ethics. She is the past Clinical Director of the Cancer Survivorship Center at Memorial Sloan-Kettering Cancer Center, where she developed and implemented a center-wide program for cancer survivors focused on research, clinical care, professional training, and education. She's served in leadership positions at the National Cancer Institute and the Lombardi Comprehensive Cancer Center and is an author of more than 130 scientific publications.

“The Stovall Awards reception is a highlight of our year, as we honor Ellen’s legacy of advocating for everyone touched by cancer to have access to the best cancer care possible, during and after their cancer treatment. This year’s honorees exemplify her life’s work and passion: like Ellen, Phuong was diagnosed with cancer as a young adult and used her experience to help others, offering hope and support to newly diagnosed cancer survivors and advocating for patient-centered care. Mary McCabe, over the course of her distinguished career as a clinician and researcher, embraced a holistic approach to helping cancer survivors live well during and after cancer treatment. She developed comprehensive survivorship programs and advanced the field of survivorship through research, clinical care, professional training, and education.”

**- SHELLEY FULD NASSO, NCCS CEO**

# NCCS IN THE NEWS



[2023 Telehealth Research Centers of Excellence \(TRACE\) Annual Meeting | Future of Telehealth](#)

---



[Developing a Multidisciplinary and Multispecialty Workforce for Patients with Cancer, from Diagnosis to Survivorship: A Workshop](#)

---



[Assessing and Advancing Progress in the Delivery of High-Quality Cancer Care: A Workshop](#)

---



[CMS must protect access to the 'gold standard of breast reconstruction'](#)

---



[My Life Matters Magazine](#)

---



[National Cancer Survivors Day](#)

---



[Beyond Innovation, Providing Cancer Survivors What They Need to Thrive](#)

---



[Breast Cancer Resources: Where to Turn to When You Need Help](#)

---

**THE BLOODLINE WITH LLS**

A PODCAST FOR PATIENTS AND CAREGIVERS

[Give Yourself Grace: Overcoming Long-term Side Effects](#)

---



[Cancer Culture Newsletter](#)

---



**ABOVE+BEYOND  
CANCER**

[Above + Beyond Cancer Podcast](#)

---



**DEBBIE  
WASSERMAN SCHULTZ**

[2023 Cancer Survivorship Summit](#)

---



[Survivorship Survey Highlights Patient & Caregiver Needs](#)

---

**Prevention®**

[How to Navigate a Cancer Diagnosis](#)

---

# DONOR SPOTLIGHT

## Giving Support to Cancer Survivors

NCCS is grateful for the support of our donors who are an essential part of our community. With your partnership, we came together as one voice to advocate for legislation to improve survivorship, treatment, and transitions in care for all survivors.

In 2023, 83% of every dollar contributed went directly to our mission of advocating for quality cancer care for all people touched by cancer. We continue to raise awareness of the needs of cancer survivors and advocate for meaningful change.

### FIVE WAYS YOU MADE AN IMPACT THIS YEAR

**1**

Thanks to your relentless advocacy, the bi-partisan Comprehensive Cancer Survivorship Act (CCSA), was reintroduced to Congress.

**2**

Data from the 2023 State of Survivorship Survey you supported identified how caregivers differ from patients in terms of decision-making and satisfaction with cancer care.

**3**

You helped convene top researchers, clinicians, and policy experts to share progress, best practices, and the challenges ahead at the Cancer Policy Roundtable (CPR).

**4**

You made sure that patients, caregivers, and clinicians had somewhere to turn for support, resources, and advocacy training.

**5**

You helped over 350 advocates participate in the in-person and virtual CPAT Symposia where they developed advocacy skills.

**THANK YOU, OUR WORK WOULD SIMPLY NOT BE POSSIBLE WITHOUT YOUR SUPPORT.**



## Meet two loyal NCCS supporters:



### **CARMEN PACE, 1986 CLUB DONOR**

Carmen Pace is a registered nurse and an active member of the CPAT Program. Life as she knew it forever changed when she was diagnosed with breast cancer at the age of forty-two, so she understands that the cancer journey does not end once active treatment ends. Now, a thirteen-year cancer survivor, and passionate advocate, Carmen sees the value in making monthly contributions.

“I am a monthly donor because NCCS gave me the opportunity to participate in the legislative process that included advocating (or what I like to call lobbying, which is my dream job) for a cause near and dear to my heart, care for cancer patients. Plus, they keep their finger on the pulse of cancer legislation, and I want to support their work as best I can.”



### **LORETTA HERRING, NCCS DONOR**

Loretta Herring, a 2019 Elevate Ambassador, works hard in her Birmingham community to improve cancer care. She is CEO and cofounder of The Cancer Awareness Network for Children, an organization born out of the pain of her mother's untimely death due to cancer. Her own cancer journey has led her to advocate and travel to other states in this country to be a voice for the underserved population in her local community. Working as a patient advocate and alongside many researchers and scientists in the hope of finding a cure for cancer, Loretta gives to NCCS so that more cancer survivors can receive the support needed to become a vital force in their local communities.

“After participating in the NCCS CPAT program, NCCS invited me to join the Elevate Ambassador Program. Through this project, I was able to gain more insight to address the needs in my local community. During the pandemic, that need became Telehealth, a digital literacy program teaching senior cancer patients how to be tech savvy. Not only did I gain assistance to design the program, but since we started NCCS has made it possible for our organization to receive recognition and invitations to showcase our program to other national organizations.”

# THANK YOU FOR YOUR GENEROUS DONATIONS

There are so many ways to give.

- + Honor or in memory of a loved one
- + Make a monthly gift
- + Give through your donor-advised fund
- + Leave a gift in your will
- + Create your own fundraiser

**VISIT: [CANCERADVOCACY.ORG/DONATE](https://canceradvocacy.org/donate)**

**EACH AND  
EVERY GIFT  
SUPPORTS  
CANCER  
SURVIVORS**

American Society Of Clinical  
Oncology

Association of Cancer Educators

Astellas Pharmaceuticals

Astrazeneca Pharmaceuticals Inc.

Bristol-Myers Squibb Company

Charities Aid Foundation  
America

Daiichi Sankyo, Inc.

David Katz Foundation Inc

Edge Research

Eisai, Inc.

Eli Lilly And Company  
Foundation, Inc.

EMD Serono, Inc.

Exact Sciences

Exelixis

Fidelity Charitable Gift Fund

Genentech, Inc.

Genmab

GRAIL

International Cancer Expert  
Corps

Jewish Communal Fund

Johnson & Johnson Healthcare,  
Inc.

Merck

Merrill Lynch, Pierce, Fenner &  
Smith Incorporated

Morgan Stanley Gift Fund

Novartis Pharmaceuticals  
Corporation

Pfizer Oncology

Pharmaceutical Research &

Manufacturers Of America

Raymond James

Sanofi US Services Inc.

Schwab Charitable

Taiho Oncology, Inc.

Takeda Oncology

The Benevity

The Brooks Group and  
Associates, Inc.

The Original Pancake House

Vanguard Charitable

Hillary Andrews

Tracey Anthony

Neeraj Arora

Nardos Aweke

Frances Barg

Andrea Becker

Samira Beckwith

Jeanne Beesley

Ronald Berenstein

Roxanne Berger

Doug and Vicky Blayney

Donna Boss

Kimberly Bowles

Otis Brawley

Cynthia Brenner

Randall Broad

Brenda Brooks

James Brown

Suanna Bruinooge

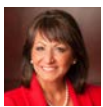
Jeffrey and Jane Bulman

Catrena Cain

Edwyna Caldwell-Mack	Harriet Granger	Lora McCann	Dagim Seyoum
Darcy Lynn Campbell	Beverly Greenfeig	Kristin McJunkins	Terlisa Sheppard
Tammy Carr	Thomas Guterbock	Yvonne McLean Florence	Mark Shostak
Crystal Champion	Alberto Gutierrez	Keisa McPartland	Tobyanne Sidman
Cheng-Shyong Chang	Ryan Hannon	Tucker Melancon	Susan Siegel
Steve Charnovitz	Molly Haring	Neil Mitchell	Jane Singer
Dale Cowan	Wendy Harpham	Wyatt Moe	SaDawn Smith
Janice Cowden	Diane Heditsian	Ahmad Molavi	Julie Song
Patrick Coyne	Amanda Helms	Gael Mooney	Natalie Stevenson
Tiffany Croteau	Jeffery Hendricks	Carol Moore	Jonathan Stovall and Briana Black
Erin Cummings	Leslie Heron	Casey Moore	Michelle Strollo
Noah Davis	Loretta Herring	Angel Moses	Kerry G. Stubbs
Davida Deutsch	Corinne Hoexter	Armik Moussissians	Cornelius Sullivan
Janet Diaz	Thelma Hoffman	Marlena Murphy	Nicole Tapay
Kevin Dorney	Barbara Hoffman	Larissa Nekhlyudov	Keene Taylor
Dana Dornsife	Marty Holtman	Kelsey Nepote	Alique Topalian
Nadine Dorvelus	Michael Holtz	Jilda Nettleton	Ruth Travis
Nicole and Brian Drost	Nina B. Homel	Brenda Nevidjon	Eric Trules
Philip DuFour	Lindsay Houff	Roberta Newmeyer	Olga Tsvetkova
Sally Eggleston	Nancy Howe	Sammantha McDonald	Samuel Turner
Rebecca Esparza	Laurie Isenberg and Joel Roos	Marsha Ohayon	Nancy Van Antwerp
Cora Fahy	Marina Ivanovskaya	Carmen Pace	David van Hoogstraten and Michelle Kayon
Sharon W. Farber	Elena Jeannotte	Jeffrey Passel	Arti Varanasi
Rachel Ferraris	Patricia Jewell	Frances Penan	Marilyn Vecchio
Taylor Ferrell	Adrienne Johnson	Carolyn Penny	Denise Villagomez
Jayla Fields	Judith M. Kahn	Marylu Phelan	Treavor Walden
Kristie Fields	Lesley Kailani Glenn	Liza Prior Lucy	Desiree Walker
Sandra Calloway Fields	Joanne Kelleher	Coral Ragognetti	Kathy Washburn
Sandra Finestone	Barbara Kerxton	John and Connie Rakoske	Sarah Weaver
Benjamin Fishman	Michael Kohn	Peter Rez	Anne Weiher
Holly and George Flesh	Cynthia Korisky	Lisa D. T. Rice and Thomas Thompson	Susan Weiner
Valerie Fraser	Melissa Kritzell	Sharon Rivera Sanchez	Sandy G. Welton
Erica Frost	Katharine Kropp	Daria Ross	Jessica Whorton
Liza Fues	Amy Lamb	Bethany Ross	Michelle Wiesner
Linda Fulbright	Lou Lanza	Julia Rowland	Brett Wilson
Steve and Jan Fuld	Scott Leader	Wanda Rusiecki	Marjorie Winick
Jane Fuld	Susan Leigh	Tiffany Ruth	Eleanor Winter and Dan Backo
Shelley Fuld Nasso and Michael Nasso	Deborah Lewis	Sally Sachar	Lisa Wise
Patricia Ganz	William "Kirby" and MaryAnn Lewis	Robert Sachs	Kiana Wooten
Joan Gargaro	Vernon H Liang	JV Sapinoso	Steve Wosahla
Suzanne Gauvreau	Ana Maria Lopez	Marianne Sarcich	Alison Wylegala and Steven Lewis
Stephanie Gayhart	Alexandra Lucy	Sheena Saydam	Robert Young, MD
Mary Glen	Peggy Lundquist	Robert Schaper	Alan Zausner
Betsy Glosik	Craig Lustig	Iris Schiff	Brad Zebrack
Sharry Goode	Jennifer Malin	Elizabeth Schiff	Lorraine Zocchi
Victoria Goode	Heather Marsh	Leslie Seeman	
Eric Gordon	Julia Maues	Joan Seidel	
Elizabeth Goss	Lauren McCaffrey	Woulita Seyoum and Ayelework Awoke	

# NCCS LEADERSHIP AND STAFF

## BOARD OF DIRECTORS



**Samira K. Beckwith**



**Otis W. Brawley, MD**



**Philip Dufour**



**Taylor Ferrell**   
Finance Committee



**Ben Fishman**



**Laurie Isenberg**   
Board Chair



**Michael L. Kappel**   
Finance Committee Chair



**Ana Maria Lopez, MPH MD**



**Lisa D. T. Rice, SM**   
Vice Chair



**Julia Rowland, PhD**  
Secretary



**Eleanor Winter**

## STAFF

**Zach Biondo**  
Digital Media & Web  
Development Manager

**Nadine Dorvelus**  
Operations & Events Associate

**Elena Jeannotte**  
Vice President of External Relations

**Kara Kenan**   
Communications & Marketing Manager

**Shelley Fuld Nasso, MPP**  
Chief Executive Officer

**Veronika Panagiotou, PhD**   
Advocacy & Programs Manager

**Woulita Seyoum**  
Senior Director of Finance & Operations

**Haley Smoot**  
Director of Public Policy

**Etsegenet Tekeste**  
Senior Accountant

**Karen Wilson**  
Development Manager

Cancer Survivor







NATIONAL COALITION  
FOR CANCER SURVIVORSHIP

8455 Colesville Road, Suite 930  
Silver Spring, MD 20910

(877) 622-7937

[info@canceradvocacy.org](mailto:info@canceradvocacy.org)

[canceradvocacy.org](http://canceradvocacy.org)