NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

Annual Report 2022

National Coalition for Cancer Survivorship

2022

Annual Report

Table of Contents

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

NCCS

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

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

Dear Friends,

As we look back on the past year, we are proud to report that 2022 was a year of growth, resilience, and meaningful progress for NCCS and the cancer survivorship community. While we continued to face ongoing challenges from the pandemic, we also found ways to adapt and innovate, enabling us to advance our mission of advocating for cancer survivors and their loved ones.

One of our most exciting achievements was the return to in-person events. The CPAT Symposium in June was a highlight of the year, bringing together advocates, survivors, caregivers, and medical students. It was truly a joy to see long-term members of the NCCS family, as well as new stakeholders, after two years of virtual events. The energy in the room was palpable, and many advocates said it was our best Symposium to date. We also hosted a virtual Symposium, to share the opportunity to learn and network with those who were not ready or able to travel. We conducted 89 virtual Hill visits to meet with lawmakers and share our vision for a world where all cancer survivors receive quality care and support.

In addition to these events, we convened two Cancer Policy Roundtables, engaging a diverse range of stakeholders in important discussions about the challenges facing cancer survivors and the policies and programs needed to support them. We discussed topics such the Cancer Moonshot, changes in cancer care related to the pandemic, medical debt among cancer survivors, and the intersection of palliative care and survivorship care. More than 80 organizations participated in these roundtables, sharing insights and partnering to drive progress. We are grateful for the participation of all who contributed to these events, and we remain committed to working collaboratively with the entire cancer community to achieve our shared goals.

This year, we conducted our fourth annual State of Survivorship Survey. The insights and data from the survey continue to illustrate the challenges facing cancer survivors during and after treatment. What we learn each year from the survey informs all of our work, as well as our policy efforts and communication with policymakers. The results confirm that the work of NCCS is more important than ever. We are committed to continuing to advocate for the needs of cancer survivors and their loved ones, ensuring their voices are heard and their concerns are addressed.

Thank you for your continued support of NCCS and our mission. We could not do this important work without you, and we look forward to continuing to work together to advance the cancer survivorship cause in the years ahead.

Sincerely,

Shelley

Shelley Fuld Nasso
CEO, National Coalition for Cancer Survivorship (NCCS)

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 living with, through, and beyond a cancer diagnosis.

2022 was a groundbreaking year in many ways, most notably, the return to in-person events. We convened stakeholders from across the cancer community at our fall and spring Cancer Policy Roundtable events, returned to in-person training for Elevate Ambassadors, and brought together survivors and caregivers to advocate for critical cancer survivorship policies.

Additionally, we worked to address the inequities highlighted in our 2022 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 and Survivorship Champions programs grew in 2022, highlighting 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 expertsand 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: 2022

NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

Amplifying Survivors' Voices

THE PATIENT PERSPECTIVE

In the 2022 State of Survivorship Survey, we delve in to 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.

The research, conducted with Edge Research in the spring of 2022, helps NCCS build on and track findings from previous years to better understand the differences in patient and survivor attitudes, experiences, and needs. Survey respondents represented 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 likely to feel empowered to be active in their care, and were better able to find a range of support systems.

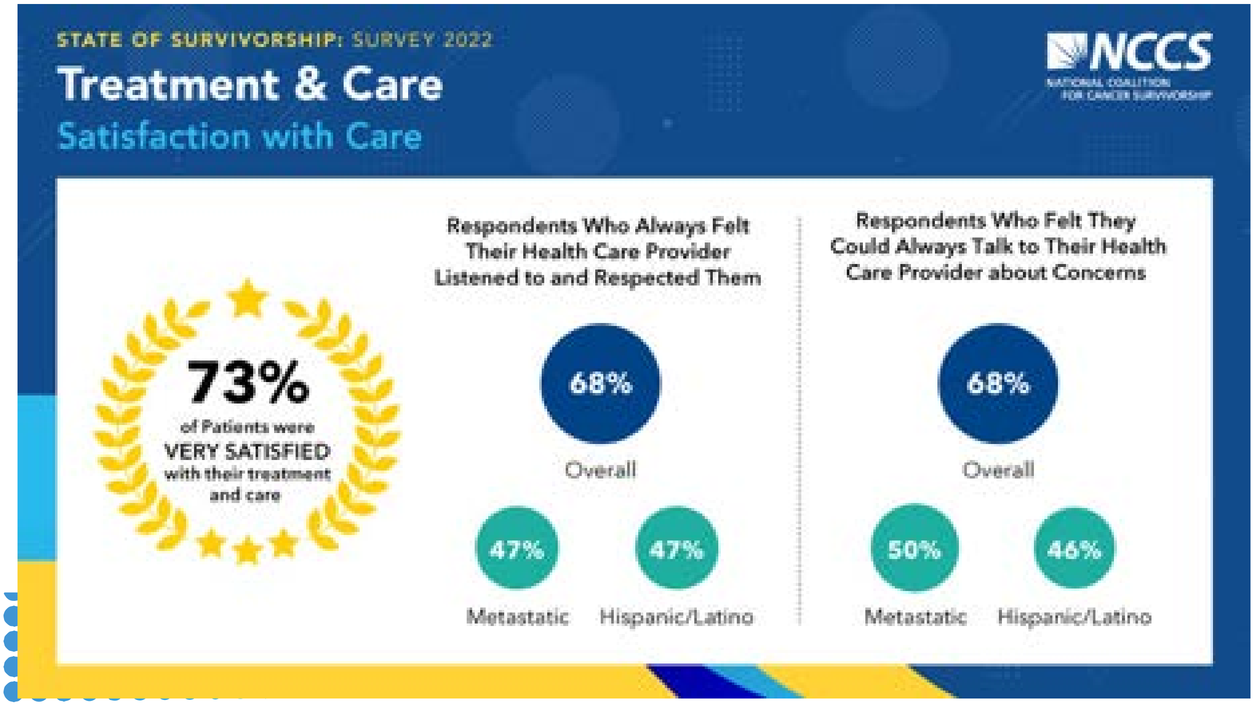
The 2022 State of Survivorship Survey demonstrates that when patients receive coordinated and high quality care, have excellent support, and have financial resources or assistance to alleviate worry about medical costs, they are more likely to have positive experiences and outcomes.

> **We wanted to understand disparities in the quality of care assessed by different demographic groups. We also asked about the physical, emotional, and financial costs of cancer and support systems that help patients and survivors throughout their journey.**

As demonstrated in survey results in previous years, majorities of patients express a high degree of satisfaction with their cancer journey; however, it is clear in qualitative discussions that there is a disconnect with the many difficulties they describe. To better understand this dynamic, we segmented survivors into three categories by experience: those who have had primarily positive experiences during their cancer journey, mixed experiences, and mostly negative experiences.

We found that people of color, younger individuals, people living with metastatic cancer, and survivors with lower socioeconomic status (SES) are more likely to be in the Mixed Experience and Negative Experience segments. Additionally, these patients struggle more at each phase of their cancer journey.

Our 2022 survey shows us where there are gaps in care and support, resulting in unequal outcomes for cancer survivors. Our work has never been more urgent.



STATE OF SURVIVORSHIP: SURVEY 2022

Treatment & Care

Satisfaction with Care

NCCS
NATIONAL COALITION FOR CANCER SURVIVORSHIP

73% of Patients were VERY SATISFIED with their treatment and care

Respondents Who Always Felt Their Health Care Provider Listened to and Respected Them

68% Overall

47% Metastatic

47% Hispanic/Latino

Respondents Who Felt They Could Always Talk to Their Health Care Provider about Concerns

68% Overall

50% Metastatic

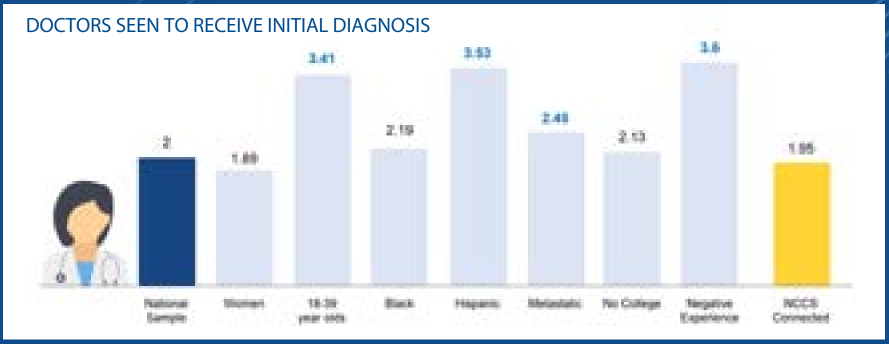
46% Hispanic/Latino

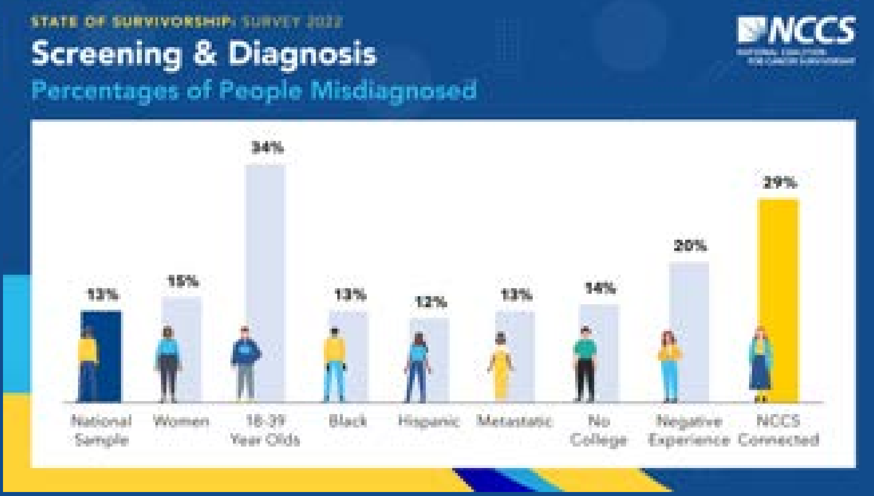
Screening and Diagnosis

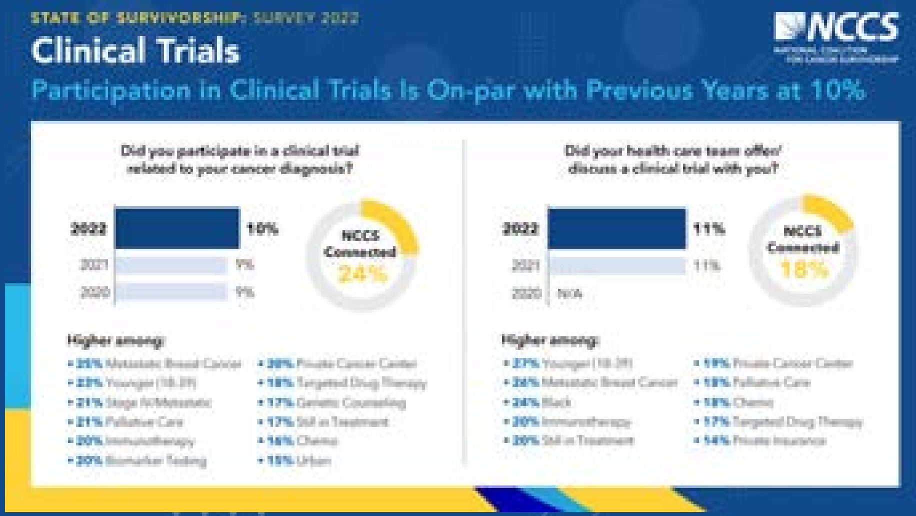
On average, patients see two doctors before getting their initial diagnosis, though People of Color, younger survivors, and people living with metastatic cancer tend to see more.

Slightly more than 10% report an initial misdiagnosis. Misdiagnosis is 2.5x more likely among 18-39 year olds than other patients. The NCCS connected group is 2x as likely to have had a misdiagnosis.

Participation in clinical trials is on-par with previous years at 10%.







Clinical Trials

Participation in Clinical Trials Is On-par with Previous Years at 10%

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

Higher among:

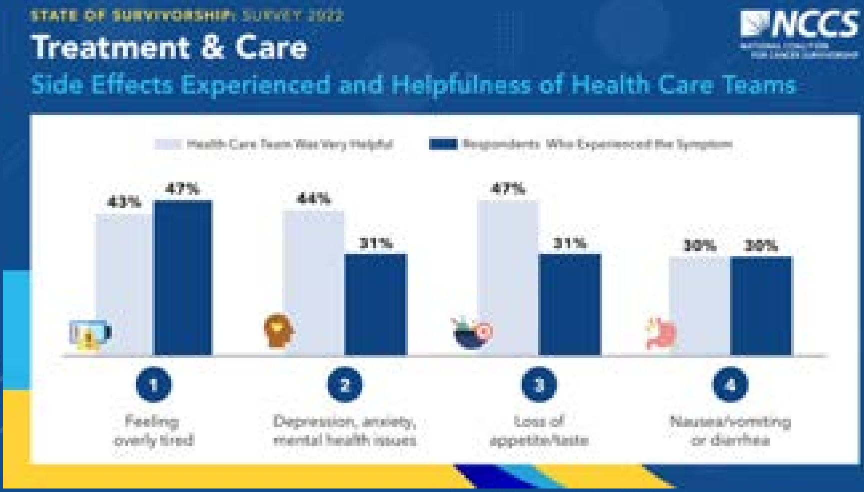
- 25% Metastatic Breast Cancer
- 23% Younger (18-39)
- 21% Stage IV/Metastatic
- 21% Palliative Care
- 20% Immunotherapy
- 20% Biomarker Testing
- 20% Private Cancer Center
- 18% Targeted Drug Therapy
- 17% Genetic Counseling
- 17% Still in Treatment
- 16% Chemo
- 15% Urban

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

Higher among:

- 27% Younger (18-39)
- 26% Metastatic Breast Cancer
- 24% Black
- 20% Immunotherapy
- 20% Still in Treatment
- 19% Private Cancer Center
- 18% Palliative Care
- 18% Chemo
- 17% Targeted Drug Therapy
- 14% Private Insurance

Treatment and Care



STATE OF SURVIVORSHIP: SURVEY 2022

NCCS NATIONAL COALITION FOR CANCER SURVIVORSHIP

Treatment & Care

Side Effects Experienced and Helpfulness of Health Care Teams

STATE OF SURVIVORSHIP: SURVEY 2022

NCCS NATIONAL COALITION FOR CANCER SURVIVORSHIP

Treatment Symptoms

A Majority of Survivors Still Experiencing Symptoms Today

STATE OF SURVIVORSHIP: SURVEY 2022

NCCS NATIONAL COALITION FOR CANCER SURVIVORSHIP

Pressure from Others to Remain Strong

As One Hispanic Respondent Shared

> I will love to go to group therapy or something with other women that have been through this, because if I talk to my family, **I have to be strong... I feel like I have to pretend like it's going to be okay.** Like I'm just getting a tooth pulled out.

Female, younger, and less-educated patients are disproportionately affected by treatment symptoms. Oncologists and surgeons get high ratings on helpfulness, while PCP's get lower scores.

60% of survivors still experience symptoms today. More than half of respondents continue to experience symptoms 10 or more years after treatment.

Few feel a stigma around their cancer diagnosis; however, younger, female, Hispanic, and people living with metastatic cancer are less comfortable telling people they have/had cancer and/or feel more pressure to remain "strong" during treatment.

Post-treatment Care

While majorities say they are very satisfied with their post-treatment care, this is still 10 percentage points lower than satisfaction with in-treatment care; and less than half say their provider did a very good job helping them make the transition.

Among those reporting negative experiences, there are several areas where they want to see their post-treatment care team be more proactive. The negative experience group is 2x more likely to report that they don't discuss any of the topics with their health care provider post-treatment.

STATE OF SURVIVORSHIP: SURVEY 2022

NCCS

Post-Treatment Care

Topics That Survivors Discuss with Their Health Care Provider Post-Treatment

STATE OF SURVIVORSHIP: SURVEY 2022

NCCS

Negative Experience Feedback

Words Used to Describe Care

“Bullied

“Telling me I was over-reacting

“Felt like a test subject

“If you had better insurance, we would have taken better care of you

”Ignored

”Number instead of a patient with individual needs

”Rushed

”Acted as if I was lying about my symptoms

The Costs of Cancer

DOCTORS SEEN TO RECEIVE INITIAL DIAGNOSIS

STATE OF SURVIVORSHIP: SURVEY 2022

Physical, Financial, & Mental Health Concerns

Top Concerns of People Living with Metastatic Cancer

PHYSICAL	Maintaining a healthy weight	67%
	Having the energy to make it through the day	74%
	Managing ongoing side effects from treatment	74%
FINANCIAL	Cost of medical care (including premiums and copays)	67%
	Cost of prescriptions and treatments	64%
	Cost of non-medical expenses	64%
EMOTIONAL	Uncertainty about the future	69%
	Being there for your family and friends	70%
	Changes to daily lifestyle/activities	68%

STATE OF SURVIVORSHIP: SURVEY 2022

Experienced Financial Sacrifices

Nearly Half of Respondents Reported Experiencing Financial Hardships and Making Employment And/Or Educational Sacrifices

Overall	Young Adults	Metastatic	Hispanic/ Latino	Blacks
49%	76%	74%	69%	63%

The same issues consistently rise to the top among survivors' physical, financial, and mental health concerns. In 2022, more survivors reported feeling concerned about almost all of these issues. In fact, a third or more are concerned about almost every item out of 30 items tested.

Nearly half of respondents have been impacted financially by cancer. That number goes up among young, Black, Hispanic, metastatic and less-educated patients, and those with mixed or negative experiences.

Advancing Policy

In 2022, 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. 9565 and S. 5295, the Comprehensive Cancer Survivorship Act, comprehensive bipartisan legislation intended to improve survivorship care.

This legislation addresses the health of cancer survivors throughout the entire continuum of care — from diagnosis to active treatment and post-treatment — and aims to close many of the gaps survivors face in order to improve survivorship, treatment, and transition. This comprehensive legislation will

- Provide coverage for cancer care planning services,
- Develop comprehensive navigation services,
- Establish employment assistance grants,
- Promote 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

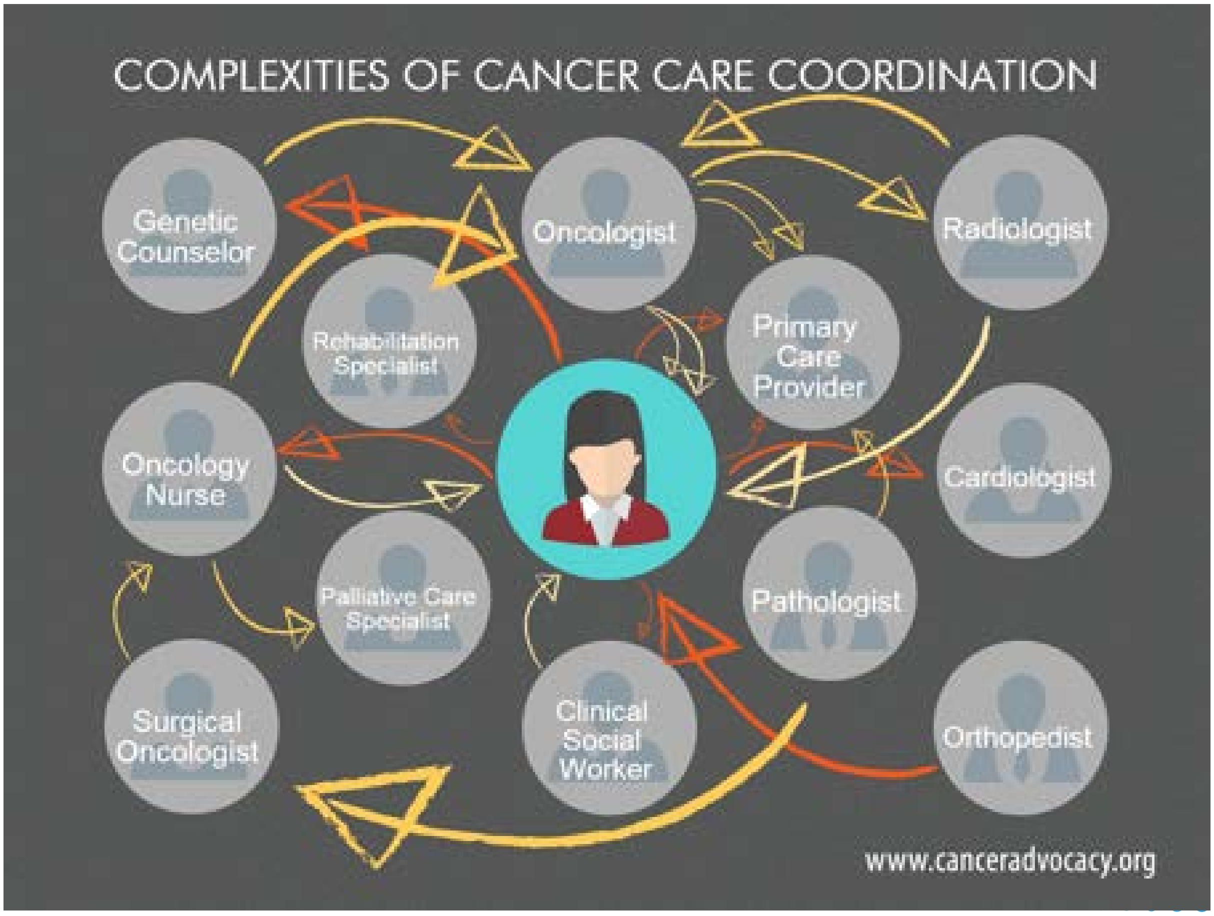
Congressman Mark DeSaulnier (D-CA), a cancer survivor, and Congressman Buddy Carter (R-GA) introduced H.R. 4414, the Cancer Care Planning and Communications Act (CCPCA), bipartisan legislation to establish a Medicare service for cancer care planning.

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, coordinates 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.

Most cancer patients still do not receive a written plan that explains 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.

In fact, in our 2020 State of Cancer Survivorship Survey, only 17% of cancer survivors nationwide reported receiving a survivorship care plan. 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 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.

> **For a cancer survivor, dealing with the collateral damage of cancer treatment and the continued surveillance for recurrence or secondary cancers, going without insurance is simply not an option. We simply can't go back to the days before the ACA when cancer survivors could be denied coverage, and we must ensure people have access to quality, affordable health insurance.**
>
> *-Michael Kappel, NCCS board member and 13-year colon cancer survivor*

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 indiivuals 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 2022, 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.

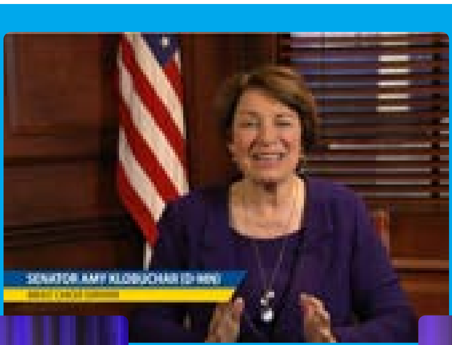
Patients and Caregivers for Paid Leave: A national coalition of patient advocacy organizations and partners advocating for paid family and medical leave for people living with and/or caring for individuals who have a serious illness or health condition.

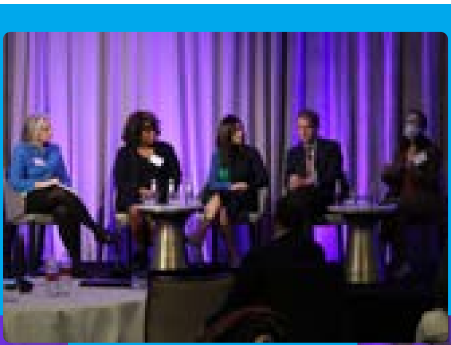
Engaging with Policymakers

For the past 22 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 2022

NCCS brought together experts and cancer survivors to discuss lessons learned from cancer care during the pandemic and options to improve the delivery of care, including a closing keynote from NCI Director Ned Sharpless, MD. The White House Office of Science and Technology Policy's Danielle Carnival, PhD, shared the message of hope that drives the reignited bipartisan Cancer Moonshot effort. Also, Senator Amy Klobuchar (D-MN), a cancer survivor, spoke about her breast cancer diagnosis during the pandemic and announced her partnership with Congresswoman Debbie Wasserman Schultz (D-FL), a fellow cancer survivor, to introduce cancer survivorship legislation that would ensure a seamless continuum of care for all survivors.





and Leadership

CANCER POLICY ROUNDTABLE — FALL 2022 FALL 2022

Congresswoman Debbie Wasserman Schultz (FL-23) delivered a keynote address and revealed bipartisan support for her legislation, the Comprehensive Cancer Survivorship Act. Panel discussions addressed the future of health policy, the mid-term elections' effects on cancer survivors, and the burdens of financial toxicity and medical debt. Featured presentations by Ellen L. Stovall awardees included Patricia Ganz, MD, on the importance of palliative care in survivorship care, and Alicia Staley on survivorship and advocacy. Newly-appointed National Cancer Institute (NCI) Director, Monica Bertagnolli, MD, highlighted NCI's commitment to improving care and quality of life for survivors through research and called for a renewed focus on addressing disparities in care for survivors.

Rising to the Occasion for

The CPAT program currently engages almost 900 cancer advocates, including survivors and caregivers, and welcomed 177 new members to CPAT in 2022.

ADVANCED TRAINING FOR ADVOCATES

In-Person Symposium

The 2022 Cancer Policy & Advocacy Team (CPAT) Symposium was our 9th annual event and marked the return to in-person meetings for NCCS advocates. We welcomed 55 participants, including advocates, caregivers, and medical students from the CUPID (Cancer in the Under-Privileged Indigent or Disadvantaged) Program at Johns Hopkins, Indiana, and The Ohio State Universities. Rising second-year medical students in the CUPID program have attended the Symposium every year since 2016, an important collaboration that benefits both advocates and students alike.

The CPAT Symposium provides its members with training on health care policy, advocacy, and communication skills. During the three-day event, attendees had the opportunity to learn, share experiences, and support each other. The atmosphere was lively, with plenty of laughter and a few emotional moments. Many participants felt that this was the most successful CPAT Symposium yet, as the positive energy was palpable throughout the event.

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

- "Music as Care" - the role of music, arts, and self-expression in supporting health and healing. Presented by Tamara Wellons, Smith Center for Healing and the Arts.
- Advocate Panel Discussion: CPAT members Kimberly Bowles, Michael HOltz, and Nicole Bullock shared their personal cancer stories and advocacy strategies.
- Framework for providing medical care with cultural humility. Presented by Lori Wilson, MD, FACS, Howard University.
- Healthcare policy outlook for 2022 including medical debt and value-based payment models. Presented by a panel of policy experts, including: Anne Hubbard, American Society for Radiation Oncology, Rebecca Kirch, National Patient Advocate Foundation, and Haley Smoot, NCCS Director of Public Policy

Advocates

- Benefits of integrative oncology and evidence-based integrative practices. Presented by the CPAT Steering Committee members Lesly Kailani Glenn and Desiree Walker, and moderated by NCCS board member Dr. Ana Maria Lopez.
- Resiliency and Legacy. Presented by Alique Topalian, PhD, MPH, University of Cincinnati.
- Storytelling and Telling Compelling Stories. Presented by Andrew Conte, PhD, Point Park University.
- Lessons learned from a career in palliative care and supportive oncology. Presented by Thomas J. Smith, MD, Medical oncologist and palliative care specialist.
- Difficult conversations between physicians and patients. A role Play Exercise, CUPID program medical students and CPAT advocates.

Virtual Symposium

NCCS organized a Virtual Symposium in July 2022 for those who could not participate in the in-person event. U.S. Rep. Mark DeSaulnier (CA-11) opened the symposium with a presentation on the Cancer Care Planning and Communications Act, which he introduced to establish a Medicare service for cancer care planning. The virtual symposium also featured a workshop on self-care and self-love as coping skills for mental health and healing, facilitated by Ta'lor L. Pinkston, LSW, MSW, BA. Pinkston discussed the six ways to take care of oneself, including emotional, physical, mental, spiritual, social, and practical self-care. The Virtual Symposium also included Hill Week send-off with U.S. Rep. Jamie Raskin (MD-8), where he talked about his experience as a legislator diagnosed with cancer and shared tips for communicating with lawmakers about important cancer survivorship legislation.

> "I must say, I always enjoy 'getting an inside look at the Hill' from Reps. DeSaulnier and Raskin regarding 'the temperature' on the Hill and tips to prepare for NCCS Hill Day. Equally important are their personal stories as survivors and how their lived experiences inform their work and commitment to aid NCCS in fulfilling its mission. " — Desirée A.H. Walker

NCCS brings together nearly 900 patient advocates to inform the work we do and the resources we create. As members of CPAT, advocates affect change in the cancer community by engaging in opportunities at the local and national levels.

EMPOWERING ADVOCATES

NCCS nominates CPAT members for certain opportunities, and we encourage them to partner with researchers to share their perspectives as cancer survivors on boards and summits within government agencies, partner organizations, and professional societies.

In 2022:
Advocates served NCCS as members of:

- Cancer Rehabilitation Working Group
- Integrative Oncology Working Group
- Young Adult Working Professional Group
- Recommendations for CMMI Enhancing Oncology Model Working Group

NCCS advocates also supported various panels and podcasts, including:

- Maine Cancer Series
- Stupid Cancer's Digital CancerCon
- Indiana University's Virtual Cancer Advocacy Panel
- CPAT Webinar: Care and Career Support: From Health Systems to Employers
- CPAT Webinar: Survivorship Needs for People Living with Advanced and Metastatic Cancers
- The Survivorship Center Podcast on Living with Metastatic Cancer
- The Leukemia and Lymphoma Society's Podcast

We nominated advocates for important roles, including:

- DoD Breast Cancer Research Program: Consumer Peer Reviewer
- DoD Rare Cancer Research Program: Consumer Peer Reviewer
- SWOG Cancer Research Patient Advocate Committee Member
- FDA Patient Engagement Collaborative
- Cleveland Clinic Fellowship in Advanced Bioethics
- Central Michigan University MPH Program

Stories of Survivorship

"Do what makes you happy — something that you're passionate about. Pay it forward, and try to make things better for someone that's coming after you."

Nicole C. Bullock

Nicole Bullock's mission is to promote self-advocacy. Nicole understood early in her advocacy journey that increasing Black cancer patients' participation in clinical trials is one step toward increasing the number of long-term survivors in the future. This goal was also personal for Nicole, as someone who wasn't represented in studies on the medication doctors prescribed her.

Nicole, a 7-year survivor of stage 2B mediastinal diffuse large B-cell non-Hodgkin lymphoma, founded the Nicole Cares Foundation, an organization which recognizes that addressing the health disparities that lead to poor outcomes among Black cancer patients is key to ensuring that all patients feel empowered throughout their care.

Nicole began volunteering with NCCS in the summer of 2022, when she spoke about the Nicole Cares Foundation on a panel at the in-person CPAT Symposium. While there, Nicole networked with advocates from across the country, listened to their stories, and learned about the work they're doing in their communities. She connected with others who were also misdiagnosed and learned more about legislation affecting cancer survivors. Nicole also participated in NCCS's Virtual Hill Week, where she met with the office of Congresswoman Robin Kelly to advocate for H.R. 4414, The Cancer Care Planning and Communications Act, using her personal experience to discuss the importance of survivorship care plans.

Michael Holtz

Already an advocate for cancer survivors at the time of his diagnosis, Michael Holtz knows the power of using his personal narrative and his skills as a Communications and Marketing specialist to advance the needs of cancer survivors. He believes everyone has a place in the advocacy community.

Michael, and 11-year colorectal cancer survivor, is an active advocate. He was named ACS CAN's State Lead Ambassador of the Year in 2019 and received the Volunteer Award for Excellence in Advocacy, their highest volunteer honor, in 2021.Michael also serves on the board of the Cancer Support Community of East Tennessee. He is a Fight CRC 2023 Ambassador, a patient advocate for scientific peer review programs for the Colorectal Cancer Alliance, and a member of NCCS's Cancer Policy and Advocacy Team (CPAT).

Michael's advice for survivors is to find a way to use their experience to help others. Since the day he was diagnosed, Michael has been open about his cancer journey and the advocacy work in which he's involved. He shares his story in every possible venue, including on stage, with the media, on podcasts, and with lawmakers. They need to hear from the people who are living the experience. He knows not everyone is comfortable being so open, but everyone has a place in the advocacy spectrum, and organizations like NCCS are looking for survivors to get involved at their comfort level.

"Lawmakers are inundated with statistics, rhetoric and policy-speak. What they need to hear, and what they appreciate, are the lived experience stories from their constituents. It makes a difference, and it matters."

Awarding 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 2022, NCCS presented the 7th annual Stovall Award to Patricia A. Ganz, MD, and Alicia Staley.

"As one of NCCS's founders, Dr. Patricia Ganz has been a leader of the survivorship movement for decades. She has been instrumental in developing the field of cancer survivorship, advancing the science, advocating for guidelines and policy change, and mentoring investigators and clinicians who contribute to the research and care of cancer survivors. She is truly an innovator in patient-centered care and a deserving recipient of the Ellen L. Stovall Award.

"Alicia Staley has a cancer story and journey similar to Ellen Stovall's. Like Ellen, Alicia has dedicated her life to advocacy – helping other cancer survivors navigate their treatment and survivorship, connecting advocates with researchers, and making sure that people touched by cancer have a seat at the table when decisions are made. As a co-founder of the breast cancer social media (#BCSM) community, Ms. Staley created a worldwide network of patients, advocates, caregivers, clinicians, and researchers, providing support and advocating for better cancer care."

— NCCS CEO Shelley Fuld Nasso

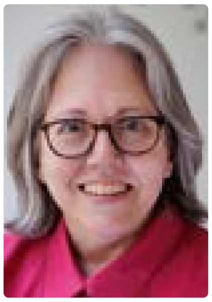
PATRICIA A. GANZ, MD, RECIPIENT OF THE HEALTH CARE PROVIDER AWARD

Patricia A. Ganz, MD, is a medical oncologist and Distinguished Professor of Medicine at the UCLA School of Medicine, where she has been on the faculty since 1978. She is also a Professor of Health Policy & Management at the UCLA School of Public Health. Dr. Ganz was a founding member of the National Coalition for Cancer Survivorship (NCCS) in 1986 and has served on various advisory boards and committees, including the National Cancer Institute Board of Scientific Advisors and the American Society of Clinical Oncology Board of Directors. She has received numerous awards for her work in cancer survivorship and patient outcomes and is the Editor-in-Chief of the Journal of the National Cancer Institute. Dr. Ganz's research interests include cancer survivorship and the late effects of cancer treatment, patient-reported outcomes in clinical trials, and quality of care for cancer patients.

As one of the original members of the cancer survivorship ‘movement,’ Dr. Ganz has been instrumental in driving the field toward where it is today. Through her own groundbreaking research, compassionate clinical care, and dedication to mentoring countless individuals, Dr. Patti Ganz has built, guided, and supported the field of patient-centered cancer survivorship care.”

— Larissa Nekhlyudov, MD, MPH, Professor, Brigham & Women’s Hospital, Harvard Medical School, Clinical Director, Internal Medicine for Cancer Survivors, Dana-Farber Cancer Institute

ALICIA STALEY, RECIPIENT OF THE PATIENT ADVOCATE AWARD



Alicia C. Staley is the Vice President of Patient Engagement at Medidata, where she created Patient Centricity by Design (PCbD) to develop patient-centric technical solutions. She is also a three-time cancer survivor and collaborates with patient advocates and non-profit organizations to improve processes and policies that impact cancer care. With over 20 years of experience in software design and information systems management, Alicia has co-led numerous research studies on patient engagement and published papers on patient-centric approaches to clinical trial design and development. An early adopter of social media, she co-founded #BCSM, which attracts over 250 global participants each week to its scheduled online discussions. This foundational online social media support channel is recognized as the gold standard for disease-specific social media networks.

She has a Mechanical Engineering degree from Syracuse University and a Masters of Information Systems and an MBA from Boston University. In 2021, she won the CHI SCOPE Participant Engagement award for her work on Medidata's Patient Centricity by Design initiative.

“While Alicia maintains an active role locally, her influence as a leader is well beyond her geographic location. Her advocacy reaches a national and, in fact, a global audience. Alicia has been and continues to be highly effective as a community builder, a collaborator, and a facilitator within groups of people seeking to improve care for cancer patients and their families. Her first-hand knowledge of cancer care and delivery after three separate primary diagnoses spanning several decades has afforded her a unique perspective and a variety of experiences which she infuses into everything she does.”

— Anne Marie Mercurio, Patient Research Advocate







NCCS presented the 7th annual Ellen L. Stovall Award to Patricia Ganz, MD and Alicia Staley for their innovation and dedication to cancer survivors.










NCCS


NCCS


NCCS
NATIONAL COALITION FOR CANCER SURVIVORSHIP


NCCS


NCCS

NCCS in the News

OncologyNurseAdvisor
FEBRUARY 25, 2022

SHARED DECISION MAKING BENEFITS PATIENTS, CLINICIANS IN ONCOLOGY CARE

More patients than ever are becoming active participants in how they receive care. The National Coalition for Cancer Survivorship breaks down self-advocacy into multiple parts including information seeking skills, communication, problem-solving, and negotiation.4 Because nobody knows a patient better than themselves, allowing patients a voice in their care can change their outlook on their treatment journey. By creating a collaborative environment, patients are encouraged to ask cultivated questions to fully understand their treatment.

CANCER ADVOCACY, STORYTELLING, AND SURVIVORSHIP WITH DR. VERONIKA PANAGIOTOU

In this episode of Bag It's podcast, Your Guide Through Cancer, host and Executive Director, Mindy Griffith chats with Dr. Veronika Panagiotou, who currently serves as the advocacy and program manager at the National Coalition for Cancer Survivorship. She was diagnosed with Non-Hodgkin's Lymphoma a few days after celebrating her 25th birthday. Eight years later, she uses her cancer diagnosis and the knowledge she has gained through the process to empower other cancer survivors to tell their stories and support their advocacy.

Cancer bag it
20 Years
APRIL 11, 2022

DEFINE SURVIVOR

Vol 17, Issue 2 of Beyond Blue Magazine looks at the history of the survivorship movement, prominently featuring NCCS in the article "Define Survivor."

NQF LEADERSHIP CONSORTIUM ADDS IMPLEMENTATION COLLABORATIVE: GROUP WILL IDENTIFY ONE TOP HEALTHCARE QUALITY PRIORITY AND PARTICIPANTS WILL PILOT TEST STRATEGIES FOR IMPROVEMENT OVER A 12-MONTH PERIOD

NCCS CEO Shelley Fuld Nasso is acknowledged as a member of the Leadership Consortium, a forum of multistakeholder healthcare experts representing NQF member organizations. The consortium identifies actionable strategies to improve healthcare quality and drive lasting change in key areas. The group's guidance informs the direction of NQF programs and drives improvement across healthcare.

healthcare innovation
PEOPLE. PROCESS. TECHNOLOGY TRANSFORMATION.

JUNE 20, 2022

THE CANCER LETTER

JULY 1, 2022

ONCOLOGY AND HEALTHCARE GROUPS RESPOND TO THE END OF ROE V. WADE

NCCS joins professional groups, advocacy groups, medical journals, and US cancer centers, health systems, and academic hospitals to provide comments in the wake of Supreme Court decision on Dobbs v. Jackson Women's Health Organization. In the statement, NCCS encourages policymakers who are evaluating next steps in the wake of the Dobbs decision to consider the impact of their legislative and regulatory proposals on cancer patients, their families and friends, and the multidisciplinary team of cancer care professionals who treat them. They explain that limiting the flow of accurate and complete medical information and advice and blocking access to essential elements of cancer care may result in grave harm to cancer patients and may reverse progress in improving the nation's cancer outcomes.

Donor Spotlight

GIVING SUPPORT TO CANCER SURVIVORS

Facing cancer can be overwhelming. However, with the help of caring donors like you, individuals and families affected by cancer can find the support they need to navigate this challenging journey. By donating, you become an essential part of the community that helps ensure no one faces cancer alone.

Giving a gift to the National Coalition for Cancer Survivorship directly supports cancer survivors and those who care for them. One way to support NCCS is to join the 1986 Club as a monthly donor.

Your gift goes towards:

- Resources that help those with cancer from diagnosis through treatment and beyond.
- Provide education and training to health care professionals on issues important to survivors.
- Advocacy for health care policies that ensure high-quality cancer care for all.

Thank you for your support.

THE 1986 CLUB

Monthly giving goes a long way to provide the stable, consistent support NCCS needs to improve the quality of cancer care nationwide. So, join The 1986 Club today and be a part of our special community of monthly donors like Nancy and Roxanne, who are making a lasting difference in survivorship care.

NANCY HOWE, 1986 CLUB DONOR

Nancy Howe, a 26-year oral cancer survivor, and passionate survivorship advocate, understands the importance of making a difference through consistent support. Her monthly gift to NCCS aims to empower advocates working in their communities to provide essential survivorship resources to those in need. Nancy's appreciation for our Founders' vision 36 years ago to improve the care of cancer survivors grew after reading a book written by a fellow cancer survivor, which chronicled the history of the cancer survivorship movement.

“I had no idea how indebted I am — like most of us are — to the survivorship culture that NCCS built one milestone at a time, for so many years, through so many different struggles.”

Nancy believes in the power of making a monthly commitment, regardless of the amount, to provide a solid financial foundation that allows new programs to flourish. She recognizes that even small donations can make a big impact and helps NCCS continue to provide essential resources to cancer survivors and their families.

“I am not a large donor, but I think that NCCS can count on me always to be there, just as I count on NCCS to always be there for me.”

Nancy's unwavering support is a testament to her belief in NCCS's mission and to the value of survivorship culture. Her commitment to making a difference in the lives of cancer survivors and their families is an inspiration to us all.

ROXANNE BERGER, 1986 CLUB DONOR

Roxanne Berger, LPN, is a Clinical Nurse Coordinator for the Wellness After Cancer Survivorship Program at MD Anderson Cancer Center at Cooper in Camden, New Jersey. Her passion for cancer survivors is evident in her advocacy work, and as an NCCS Elevate Ambassador, strives to ensure survivors receive equitable care and education. Roxanne's monthly donations to NCCS reflect her belief in the importance of consistent support to empower advocates in their communities.

"I believe every dollar counts towards improving survivorship research, advocating for policy changes on Capitol Hill, and assisting the local breast cancer survivor who is looking to form a support group. I want to help make NCCS’ voice and footprint even bigger," Roxanne explains. "My donation has helped shape policies that improve the quality of cancer survivorship care and how it is delivered," Roxanne notes. "As a nurse, it is important to me that healthcare policies on the federal and state level are being implemented to ensure survivors receive quality healthcare."

Roxanne recognizes the impact of making a monthly commitment, regardless of the amount. She understands that even small donations can make a big difference and provide a solid financial foundation that allows survivorship programs to flourish. Roxanne's dedication to making a difference in the lives of cancer survivors and their families is truly admirable.

> “Roxanne's support is invaluable to NCCS, and we are grateful for her dedication to empowering advocates and improving survivorship care. Her work as an Elevate Ambassador and her monthly donations are a testament to her belief in our mission and her commitment to making a difference in the lives of cancer survivors and their families.”
> VERONIKA PANAGIOTOU,PhD | NCCS ADVOCACY AND PROGRAM MANAGER

> "Nancy's consistent support through her monthly gifts is a testament to her firm commitment to making a difference in the lives of cancer survivors. Her generosity empowers NCCS to provide essential resources and support to those in need, and we are grateful for her dedication to our mission."
> ELENA JEANNOTTE | NCCS VICE PRESIDENT, EXTERNAL RELATIONS

Thank You for Your Generous Donation

2022 Donors

Abbvie Inc.
Amazonsmile Foundation
American Society For Radiation Oncology
American Society Of Clinical Oncology
Amgen Inc.
Charities Aid Foundation America
Daiichi Sankyo, Inc.
David Katz Foundation Inc
Eisai, Inc.
Exact Sciences
Genentech, Inc.
Genmab
Hope Hospice and Community Services, Inc.
IBM Employee Charitable Campaign
Johnson & Johnson Healthcare, Inc.
Kite Pharma, Inc.
Merck
Novartis Pharmaceuticals Corporation
Pfizer Oncology
Pharmaceutical Research & Manufacturers Of America
Raymond James
Sanofi US Services Inc.
Select Medical Corporation
Taiho Oncology, Inc.
Takeda Oncology
The Original Pancake House
United Healthcare
Valerie Abbott
Roberto Anson
Neeraj Arora
Frances and Stan Barg
Jennifer Battle
Andrea Becker
Samira K. Beckwith
Emelda Benjamin
Ronald Berenstain
Paula and Mark Berezin
Marjorie and Egon Berg
Amy Berman
Kyle Bland
Emelia Blankson
Douglas and Vicky Blayney
Alexander Bologna
Susie Brain
Susan Bram
Otis Brawley, MD
Cynthia and Stephen Brenner
Woodrow Brokenburr
Brenda Brooks
James Brown
Suanna Bruinooge
Jane and Jeffrey Bulman
Darcy Burbage
Jessica Burris
Carly Burtnick
Stuart and Jamie Butler
Darcy Lynn Campbell
Jennifer Campisano
Doris Cardwell
Robert Carter
Cindy Cisneros
C. Norman and Karolynn Coleman
Toni Collins
Dale Cowan
Janice Cowden
Neil Cross
Erin Cummings
Michael Cunningham
Marianne Dailey
Rufus Davis
Charles de Krafft
Debbie Denardi
Davida Deutsch
Nicole Drost
Michael Drysch
Noelle Dwyer
Diane Elliott
Sharon Farber
Taylor Ferrell
Kristie and Jermaine Fields
Sandra Finestone
Benjamin and Julie Fishman
Clarita Fitzpatrick
Kathleen Flaherty
Rob Fonte
Liza Fues
Steve and Jan Fuld
Shelley Fuld Nasso and Michael Nasso
Cynthia Gagen
Patricia Ganz
Julia Garcia
Joan Gargaro
Suzanne Gauvreau
Judith Gische
Matt Goldman
Valerie Goldstein
Harriet Granger
Larrie and Joyce Greenberg
Jane and David Green
Beverly and Stuart Greenfeig
Thomas Guterbock
Alberto Gutierrez
Virginia Haessly
Kenneth Handel
Molly Haring
Wendy Harpham
Catherine Harvey Sevier and David Sevier
Diane Heditsian
Craig Ann and R. Scott Heflinger
Jeffery Hendricks
Loretta Herring
Lorraine Hiscock
Thelma Hoffman
Barbara Hoffman
Nina and Michael Homel
Norah Hourigan
Nancy Howe and Don Bierman
Elmer Huerta
Laurie Isenberg and Joel Roos
Elena Jeannotte and Angela Shetler
Patricia Jewell
Debra Johnson
Gloria Johnson
Katrina Johnson
Lee Jones
Sharon Jones
Michael and Kim Kappel
Susan Katz Miller
Danette Kauffman
Amy Kerschbaum

Katharine Kropp
David and Nancy Lacey
Amy Lamb
Lou Lanza
Scott Leader
Susan Leigh
Andrew Kershaw
Barbara Kerxton
Ellen and Francis Kleeman
Ralph and Lisa Kleinman
Ned Kline
Kelvin Ko
Cynthia Korisky
Howard Krongard
Stephen Lewis and Alison Wylegala
Deborah and John Lewis
Maia and Paul Linzer
Lynn Liston
Sara Littlefield
Rosemary Locke
Ana Maria Lopez
Liza Prior Lucy and Drew Lucy
Susan Luff
Peggy and Richard Lundquist
Craig Lustig
Vithal Madhira
Jennifer Malin
Linda Martin
Mary McCabe
Lauren McCaffrey
Lora McCann
Yvonne McLean Florence
Tucker Melancon and Diana Moore
Raiko Mendoza
Zareen Mirza
Neil Mitchell
Wyatt and Nancy Moe
Lisa Montez
Gael Mooney
Carol Moore
Casey Moore
Charlie Nasso
Sammantha and Gerald McDonald
Basya Pearlmutter
Jody Pelusi
Frances and Barrett Penan
Marylu Phelan
Geoffrey Pickford-Gordon
Susan Plant
John and Susu Rainey
John and Connie Rakoske
Peter Rez
Lisa Rice and Thomas Thompson
Alice Ring
Sigmund Roos and Ruthie Rohde
Bethany Ross
Julia Rowland
Eric Rowsell
Laurie Rozgonyi
Sally Sachar
Robert Sachs and Caroline Taggart
Jane Sansbury
JV Sapinoso
Robert Schaper
Susan and Leslie Scherr
Leslie Seeman
Jerome Seidenfeld and Linda Camras
Woulita Seyoum
Helina Seyoum
Dagim Seyoum
Dereje Seyoum
Tobyanne and Arnold Sidman
Susan Siegel
Jane and Arthur Singer
Christina Sisti, DPS, MPH, MS
Dawson Smith
Alicia Staley
Gina Stelnik
Lana Stevenson
Hillary Stires
Jonathan Stovall and Briana Black
Michelle Strollo
Cornelius Sullivan
Andrew Tao and Jeanne Beesley
Stuart and Frances Taylor
Gladys Thomas
Ginny Thomas-Wilson
Alique Topalian
Ruth Travis
Grace Trujillo
Eric Trules and Suryawati Manalu-Trules
Anne and Mac Turnage
Samuel Turner and Elizabeth Goss
David van Hoogstraten and Michelle Kayon
Arti Varanasi
Joann Vesole
Emily Von Scheven
Desiree Walker
M. Scott Waller
Kathy Washburn
Stefan Watson
Susan Weiner
Robert and Pearl Weiss
Sandy Welton
Gloria Wilson
Warren & Nancy Wilson
Eleanor Winter and Dan Backo
Lisa and Charles Wise
Kathleen Wortman
Harriet Young
Robert Young
Gary and Cary Zahrbock
Alan and Stacye Zausner
Barbara and Steven Zimmerman
Lorraine Zocchi

NCCS Leadership and Staff

BOARD MEMBERS

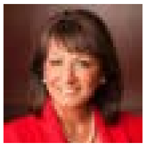

Laurie Isenberg 🎗
Board Chair


Lisa D. T. Rice, SM 🎗
Vice Chair

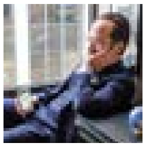

Michael L. Kappel 🎗
Finance Committee Chair


Taylor Ferrell 🎗
Finance Committee


Ben Fishman 🎗


Samira K. Beckwith 🎗


Otis W. Brawley, MD


Philip Dufour


Ana Maria Lopez, MPH, MD


Julia Rowland, PhD
Secretary


Eleanor Winter 🎗

STAFF

Zach Biondo
Digital Media and Web Development Manager

Nadine Dorvelus
Operations & Events Associate

Elena Jeannotte
Vice President of External Relations

Kara Kenan 🎗
Communications and Marketing Manager

Deborah Lewis 🎗
Director of Development

Shelley Fuld Nasso, MPP
Chief Executive Officer

Veronika Panagiotou, PhD 🎗
Advocacy and Programs Manager

Woulita Seyoum
Senior Director of Finance and Operations

Haley Smoot
Director of Public Policy

Etsegenet Tekeste
Senior Accountant

🎗 Cancer Survivor

www.canceradvocacy.org

NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

National Coalition for Cancer Survivorship
8455 Colesville Rd, Suite 930
Silver Spring, MD 20910

877-NCCS-YES
Info@CancerAdvocacy.org