

ANNUAL REPORT 2021

National Coalition for Cancer Survivorship



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

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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,

While 2020 presented us with a global pandemic that turned our lives upside down and overwhelmed our health care system with unprecedented challenges, 2021 gave us opportunities to advocate for a stronger, healthier, more prepared nation. When the world stopped, cancer continued. Cancer survivors had to endure delays in care, navigate telehealth appointments, and manage treatment without the presence of loved ones to accompany them, all while facing fears about their heightened risks due to their history of cancer.

Throughout the growing pains of the pandemic, one thing remained the same: the invaluable time spent connecting with loved ones. My family and I moved to the country with our dogs, Bingo and Maggie, who love pumpkin and peanut butter treats. We even welcomed a brood of baby chicks. Our three boys are growing taller and becoming more handsome by the day. I can't believe we have two high schoolers and a middle schooler! My oldest recently achieved the rank of Eagle Scout and will soon head to college, while the others have a few more years of enjoying life on the farm and impromptu hiking trips with Mom and Dad. As for me, I've enjoyed crushing Peloton challenges and expanding my yoga practice.

The time at home allowed us to reflect on why our founders established NCCS 35 years ago. We've continued to answer their call to advance the cancer survivorship cause by discussing pressing public policy issues, honoring leaders in health care and patient advocacy, and sharing the stories of those who make our work possible. With your support, we will continue advocating for a world where all cancer survivors are provided quality care, experience clear communication with their health care team, and have access to critical resources.

With the addition of four amazing and talented staff members, we feel incredibly motivated to implement new, creative approaches to advancing cancer survivorship. We could not do any of this work without you, our incredible staff, our Board of Directors, or our network of advocates who pound the pavement to fight for reform. Thank you for supporting NCCS throughout another challenging — yet eye-opening — year as we continued to amplify the voices of cancer survivors and their loved ones.

Sincerely,

Shelley Fuld 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 17 million Americans who share the survivorship experience living with, through, and beyond a cancer diagnosis.

NCCS experienced incredible growth in 2021. We considered innovative approaches to addressing the impact of the pandemic on cancer survivorship. Through strategic partnerships with cancer organizations, we alleviated some of the concerns of survivors who struggled to navigate a different health care landscape among the fear and anxiety of isolation.

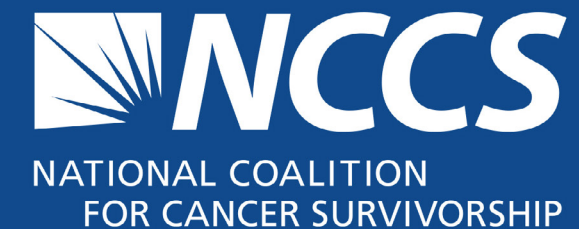
Additionally, we began to address the inequities highlighted in our 2021 State of Cancer Survivorship Survey, which showed that younger, Hispanic/Hispanic/Latino, female, and low-income patients face disparities that cause them to experience poorer care and a lower quality of life than other cancer patients.

We launched Survivorship Champions, a program for clinicians and researchers interested in improving care for cancer survivors. This community of medical professionals is a multi-directional information exchange about best practices, lessons learned, and effective models of survivorship care.

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: 2021



Amplifying Survivors' Voices

THE PATIENT PERSPECTIVE

We partnered with Edge Research to conduct the 2021 State of Survivorship Survey through 16 in-depth interviews and a nationwide survey of 1,604 patients and survivors, 500 of whom have a connection to NCCS. The research helps us build on and track findings from 2020 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. We used quotas to ensure the sample was representative of cancer patients nationally by age, gender, race/ethnicity, and region. 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.

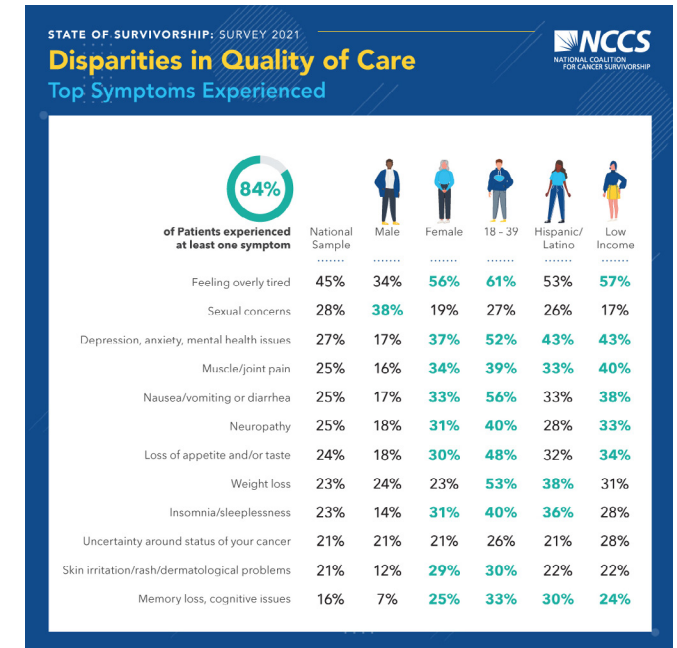
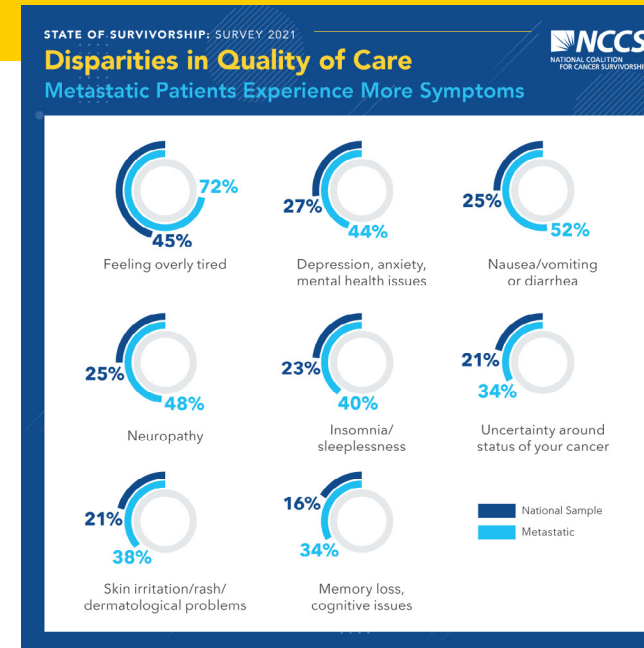
The 2021 State of Survivorship Survey demonstrates that patients who receive coordinated and quality care from their health care team, have excellent support, and have financial resources or assistance to alleviate worry about medical costs are more likely to have positive experiences and outcomes.

“ 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. We wanted to understand how the COVID-19 pandemic affected cancer care and patients' perception of telehealth appointments. Finally, we asked about the meaning of survivorship and to what degree respondents identify with the word 'survivor.' ”

SHELLEY FULD NASSO, MPP | CEO

DISPARITIES IN CARE AND QUALITY OF LIFE

Younger (ages 18-39), Hispanic/Hispanic/Latino, female, and low-income patients consistently have poorer experiences. Differences are also consistent between metastatic patients and those still in treatment, compared with those who have completed treatment.



STATE OF SURVIVORSHIP SURVEY: 2021

canceradvocacy.org | info@canceradvocacy.org | 877-NCCS-YES



The 2021 State of Survivorship Survey provides us an invaluable opportunity to delve into the cancer patient and survivor journey from a range of perspectives, and to better understand how the National Coalition for Cancer Survivorship (NCCS) can support our mission to advocate for quality care for all.

The research, conducted in partnership with Edge Research in the spring of 2021, helps NCCS build on and track findings from the previous year to better understand the differences in patient and survivor attitudes, experiences, and needs. 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). All data presented are from the national sample (n=1104) unless otherwise noted.

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 2021 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. NCCS represents more than 17 million Americans who share the survivorship experience—living with, through, and beyond a cancer diagnosis. Our 2021 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.

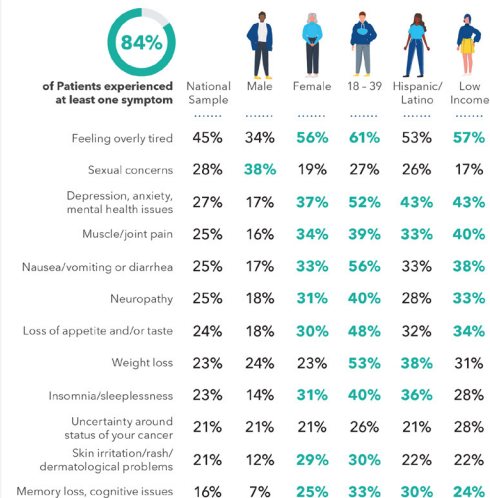
Disparities in Quality of Care

Significant disparities exist in the equity of and access to quality cancer care, with a disproportionate effect among the lower income, Hispanic/Latino, female, and young adult (ages 18-39) populations. Metastatic/Stage IV patients often have different priorities in care, particularly when it comes to quality of life.

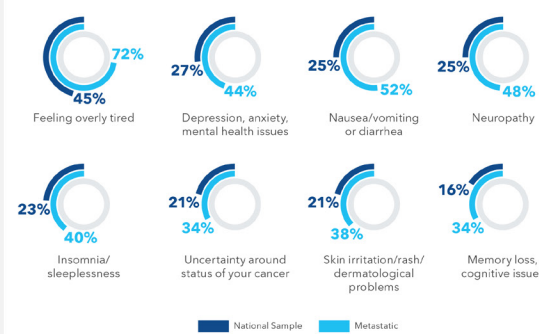
Respondents Who Rated Their Cancer Care as Excellent



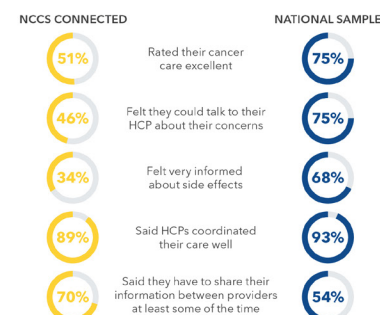
Top Symptoms Experienced



Metastatic Patients Experience More Symptoms

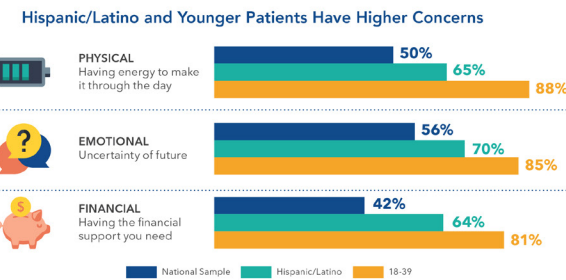


Higher Expectations/Lower Satisfaction for Connected Patients

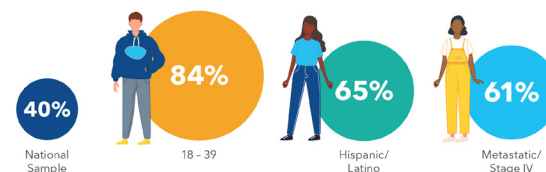


Costs of Cancer Care

The physical, emotional, and financial costs of cancer are shared by all cancer survivors, but younger, Hispanic/Latino, and female patients disproportionately report these effects.



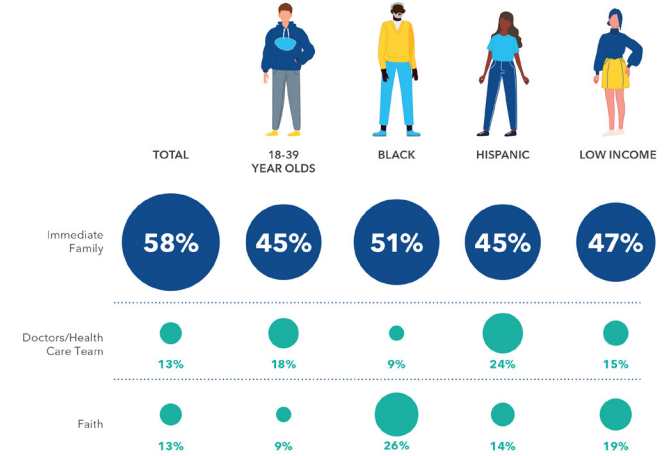
Experienced Financial Sacrifices



Support Systems Are Key

Having a support system in place to help you throughout the journey is the top piece of advice from patients. While half of respondents say their support was excellent, younger, low-income, female, and metastatic patients report having less support.

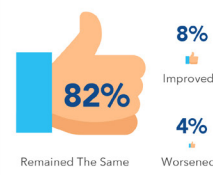
Biggest Support Systems



Treatment During COVID-19

Most say the COVID-19 pandemic did not have a big effect on their treatment and 40% were able to have telehealth appointments with their care providers. Most still prefer in-person appointments to telehealth.

Quality of Care through COVID-19



Telehealth Appointments Rated as Excellent/Very Good



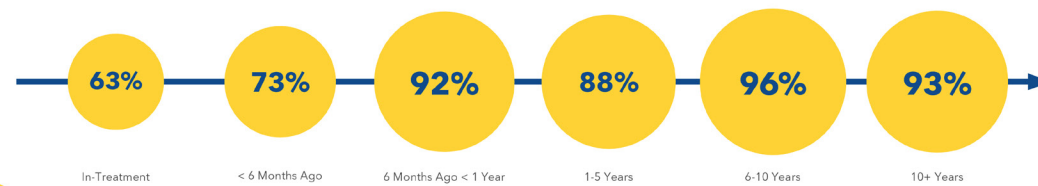
Prefer In-Person Appointments



Meaning of Survivorship

The term "survivor" remains highly relevant with 85% of respondents saying they consider themselves a survivor. The comfort level of referring to oneself as a survivor increases over time. For those in treatment, 63% consider themselves a survivor while 93% of those 10-plus years past treatment say the same.

Identification with the Term "Survivor" Grows Over Time



The State of Cancer Survivorship Amid COVID-19

JUMPING INTO ACTION FOR CANCER SURVIVORS

We joined the Cancer Leadership Council (CLC) in urging the CDC's Advisory Committee on Immunization Practices (ACIP) to review data related to the risks that COVID-19 poses to cancer survivors. We recommended including people with a history of cancer among those with high-risk medical conditions slated for vaccination in phase 1c of the ACIP schedule. We also requested that ACIP provide straightforward guidance to states about the logistics of vaccinating cancer patients and others with serious underlying medical conditions.

We ultimately recommended actions to accelerate the vaccination of cancer survivors at risk of poor outcomes from COVID-19. Cancer patients confronted confusing allocation rules and hard-to-navigate registration systems for booking vaccination appointments. The vaccination program in certain states focused on age-based allocation, which bypassed the evidence-based priority for people with serious underlying health conditions. We tirelessly advocated for cancer patients to have improved access to vaccines.

ADVOCATING FOR CANCER CARE PROVIDERS

We joined the CLC in recommending that states distribute vaccines to cancer care providers. This helped address the challenge of how patients demonstrated that they have a serious underlying health condition that qualified them for vaccination in certain states. It also ensured that cancer patients had discussions with their care team about whether they should receive a COVID-19 vaccine.

SUPPORTING HEALTH CARE WORKERS AND PROTECTING CANCER PATIENTS

The emergence of the highly contagious Delta variant, which swept through unvaccinated Americans across the country, created problems for cancer patients at risk of contracting the virus from members of their health care team. We joined other patient, professional, and research organizations of the CLC in issuing a statement in support of COVID-19 vaccination of all health care workers.

PRIORITIZING ALL TOUCHED BY CANCER

As the world began tackling COVID-19 head on, we felt the urgent need to advocate for protections for cancer survivors, those currently receiving treatment, and those administering treatment.



▲ Otis Brawley, MD

ANSWERING FREQUENTLY ASKED QUESTIONS ABOUT VACCINES

We hosted a conversation about COVID-19 vaccines with Otis Brawley, MD, cancer control expert and Bloomberg Distinguished Professor at Johns Hopkins University.

Dr. Brawley encouraged people to speak with their doctor and get vaccinated if they were able. He shared what we knew about the vaccines at the time, discussed what the vaccines meant for people with a history of cancer, and answered questions from survivors and advocates.

Advancing Policy

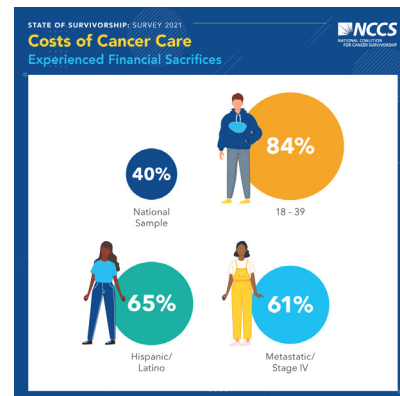
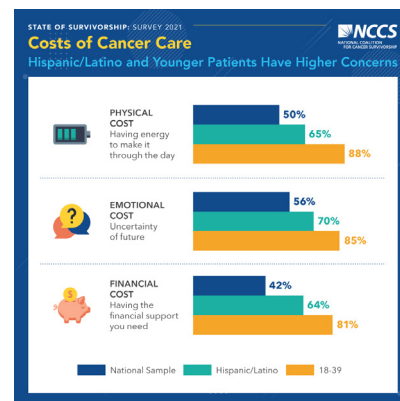
In 2021, we focused on responding to challenges that were exacerbated by the pandemic, while continuing to advocate for quality cancer care for survivors and their caregivers. Our policy priorities included:

IMPROVING CANCER CARE PLANNING

The National Academies of Sciences, Engineering, and Medicine, medical professional societies, and cancer patients embrace the idea that all patients should receive a treatment plan from their cancer care team.

HOW NCCS WORKS WITH CONGRESS TO PROVIDE CANCER PATIENTS A PLAN FOR TREATMENT AND SURVIVORSHIP:

- Congressman and cancer survivor, Mark DeSaulnier (D-CA), and Congressman Buddy Carter (R-GA) introduced H.R. 4414, the Cancer Care Planning and Communications Act (CCPCA). If passed, this bipartisan legislation will establish a Medicare service for cancer care planning. CCPCA will:
 - Provide patients with the information they need to make treatment decisions, coordinate their care, and effectively transition from active treatment to survivorship.
 - Ensure resources are used appropriately and effectively.
 - Encourage the delivery of high-quality, timely, coordinated care.



ADVOCATING FOR PAID LEAVE FOR CANCER PATIENTS AND CAREGIVERS

It is critical that cancer patients and their caregivers have access to paid leave when receiving treatment or caring for their loved one, or else they will continue to suffer physically and economically. Without a national paid leave policy, this form of immediate economic harm may have a lasting impact.

In our 2021 State of Cancer Survivorship Survey, that 43% of respondents reported that their cancer diagnosis affected their work status, with numbers significantly higher for women, Latinos, young adults, low-income survivors, people currently in treatment, and people with metastatic cancer. Nearly 10% of respondents quit their jobs, with numbers as high as 21% for some subgroups.

HOW NCCS RESPONDS TO THE ECONOMIC CONCERNS OF ALL TOUCHED BY CANCER:

- NCCS joined other advocacy groups in sending letters to congressional leadership to express support of the inclusion of a federal paid leave program, among other critical provisions, in the reconciliation bill.
- NCCS launched a social media campaign that encouraged advocates to call their senator and tell them why cancer patients and caregivers need paid leave.

STRONGER HEALTH CARE PROTECTIONS

Cancer survivors' unique circumstances require unique protections. NCCS advocated for policies that would improve health care and expand access to coverage.

HOW NCCS FIGHTS TO PROTECT CANCER SURVIVORS:

- NCCS joined the Cancer Leadership Council (CLC) in urging Health and Human Services Secretary Xavier Becerra to protect Medicare beneficiaries' access to Part D drugs in six protected classes, which include certain cancer treatments.
- NCCS joined patient, disability, and health care organizations in urging the U.S. Supreme Court to protect Medicaid and rule against work requirements.
- NCCS joined the Partnership to Protect Coverage Coalition in urging Congress and the White House to pass legislation that addresses the affordability of health insurance premiums and out-of-pocket costs, supports and expands Medicaid, and limits junk insurance plans.
- NCCS applauded the U.S. Supreme Court for their decision to dismiss the challenge to the Affordable Care Act (ACA). The legislative efforts to repeal the ACA and the legal efforts to overturn it would have been devastating for the survivors we represent, as it would have caused loss of insurance and loss of pre-existing condition protections.
- NCCS submitted comments to the Department of the Treasury, the Department of Health and Human Services, and the Centers for Medicare and Medicaid Services on the proposed Notice of Benefit and Payment Parameters for 2022. We commended the agencies for reinstating the requirement that Navigators in the federally exchanges provide education about basic concepts and rules related to health insurance coverage and how to use it. These actions met the needs of the respondents to our 2021 State of Cancer Survivorship Survey who reported needing help understanding insurance.
- NCCS joined other advocacy groups in sending letters to congressional leadership in support of the inclusion of several critical provisions in the reconciliation bill: permanently closing the Medicaid coverage gap, permanently including the enhanced advance premium tax credits in the American Rescue Plan Act, and establishing a national paid family and medical leave policy.

Congressman Mark DeSaulnier (D-CA) and Congressman Buddy Carter (R-GA) speaking at the 2019 CPAT Symposium.



Engaging with Policymakers and Leadership

SPRING 2021 CANCER POLICY ROUNDTABLE

NCCS brought together experts and cancer survivors to discuss the impact of the pandemic on cancer care, including the expansion of positive innovations in cancer care that resulted from the pandemic. We also addressed the mental health issues faced by cancer survivors before and during the pandemic, as well as changes in access to mental health care. These topics were discussed through the lens of building a more equitable health care system, considering the disparate impact of COVID-19 on Black and Hispanic Americans.

FALL 2021 CANCER POLICY ROUNDTABLE

NCCS welcomed Congresswoman Debbie Wasserman Schultz (D-FL) to discuss her cancer survivorship story and her current efforts to pursue bipartisan cancer survivorship legislation. We also presented data from our 2021 State of Cancer Survivorship Survey and spoke with an expert and advocates about the needs and challenges facing the often-overlooked Hispanic/Latino cancer survivors. The event concluded with a discussion with Dr. Emily Tonorezos, the Director of the National Cancer Institute Office of Cancer Survivorship, who shared her vision for the office and reflected on its impact over the past 25 years.

“ Just like your organization empowers survivors and helps them manage the emotional and practical and financial challenges of cancer, in my role as a federal legislator, I’m trying to change outdated policies, create new laws, shepherd new opportunities for leaders like yourselves to drive our mission home, and make sure that we think about this approach in a very personal way, because there’s nothing more personal than fighting cancer. ”

CONGRESSWOMAN DEBBIE WASSERMAN SCHULTZ (D-FL) | KEYNOTE SPEAKER

Experimentation in Cancer Care: Inspired (or Forced) by the Pandemic?

Panel Discussion



Melissa Dillmon, MD
Harbin Clinic Cancer Center



Julia Maués
Founder, GRASP



Asmita Mishra, MD
Moffitt Cancer Center

SPRING 2021
CANCER POLICY
ROUNDTABLE
APRIL 22 | NOON ET



Brenda Nevidjon, MSN, RN
Oncology Nursing Society



Deborah Schrag, MD
Dana-Farber Cancer Institute



Karen Winkfield, MD, PhD
Meharry-Vanderbilt Alliance



Shelley Fuld Nasso, MPP
NCCS (Moderator)

#CPR21



FALL 2021 CANCER POLICY ROUNDTABLE



Rep. Debbie Wasserman Schultz
Opening Keynote



Narjust Duma, MD
Dana-Farber Cancer Institute



Rebecca Esparza
Cancer Survivor



Roxana J. Guerra
Living with Metastatic Breast Cancer



Shelley Fuld Nasso, MPP
NCCS CEO



Emily Tonorezos, MD, MPH
National Cancer Institute

#CPR21

Rising to the Occasion for Advocates

NCCS hosted the 8th Annual Cancer Policy and Advocacy Team (CPAT) Symposium and Hill Week virtually in 2021.

An incredible roster of cancer survivors, health care professionals, policy experts, and more joined us to share their stories and experiences. In addition to our policy and advocacy sessions, we offered morning wellness opportunities and evening networking and entertainment.

We were thrilled to host more than 200 advocates and welcome 120 new members to CPAT.



◀ NCCS CEO Shelley Fuld Nasso moderates a discussion about treatment during the pandemic featuring (clockwise from left) NCCS Board Member Otis Brawley, MD, and CPAT Members William "Kirby" Lewis, Allison Rosen, and Desiree Walker.

NCCS CEO Shelley Fuld Nasso leads a discussion about health equity in cancer care with CPAT Members (clockwise from left) Woodrow Brokenburr, MBA, Loretta Herring, Tiah Tomlin, and Debora Denardi.



MOTIVATING AND INSPIRING ADVOCATES

NCCS hosted 15 sessions during the three-day CPAT Symposium. We explored various aspects of the survivorship experience, such as nutrition, exercise, patient advocacy, the power of visualization, and storytelling.

We shared the results of our 2021 State of Survivorship Survey, which reports cancer survivors' perspectives on disparities in care, the costs of cancer, support systems, needs of people living with metastatic cancer, and cancer treatment during the pandemic.

We welcomed to welcome members of Congress, congressional staff, and experienced advocates to share advocacy tips. This session prepared attendees for virtual Hill visits with their members of Congress.

It was an inspiring three days. Together, we gained a deeper understanding of policy issues, improved advocacy skills, and shared personal experiences with members of Congress to improve cancer care for all.

Empowering Advocates

NCCS brings together nearly 700 patient advocates to inform the work we do and the resources we create. As members of CPAT, advocates effect change in the cancer community by engaging in opportunities at the local and national level.

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.

National Coalition for Cancer Survivorship

- Benefits and Burdens of Advocacy Working Group
- Cancer Rehabilitation Working Group
- Metastatic Survivorship Working Group
- Young Adult Working Group
- Paid Family Leave Meeting with U.S. Senator Joe Manchin

Bristol Myers Squibb

- Survivorship Today Campaign
- Survivorship Today Media Tour

The Department of Defense (DoD)

- Nomination for Consumer Peer Reviewer for Rare Cancer Research Program
- Nomination for Consumer Peer Reviewer for Breast Cancer Research Program

Stanford University

- The CAN-DECIDE Study Stakeholder Summit

Oncology Nursing Society

- Developing clinical practice guidelines on adherence to oral cancer therapies

American Society for Radiation Oncology (ASTRO)

- Presentation on NCCS Telehealth Survey

CURE® Magazine

- Breast Cancer Summit Panel

National Cancer Institute (NCI)

- Living with Metastatic and Advanced Cancers Panel
- Emergency Medicine and Urgent Care Panel

ADVOCATES IN THE NEWS

NCCS CPAT members share their stories of survivorship and advocacy to advance policy and touch the lives of all affected by cancer.

Bethany Ross

National Cancer Institute

Woodrow "Woody" Brokenburr

FOX 4

Christine Hodgdon

National Cancer Institute

Nancy Howe

Jumpstart by WebMD

Sharon Rivera-Sanchez

Penn Medicine's Abramson Cancer Center

Desirée A. H. Walker

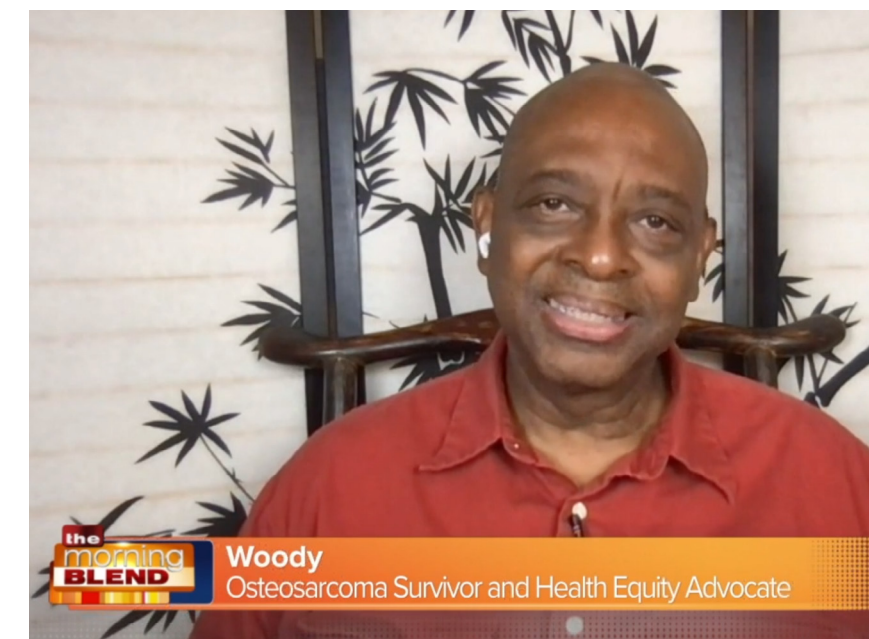
American Association for Cancer Research

American Association of Cancer Research

- Nomination for SCIENTIST - SURVIVOR PROGRAM®

Georgetown Lombardi Cancer Center

- Patient advocate on External Advisory Board



Stories of Survivorship and Advocacy

ROBERTA ALBANY

Roberta Albany's mission is to address disparities in the Black and brown cancer communities, educate others, and reduce the stigma around cancer diagnoses. She gives elected officials and other members of the cancer community two choices: either continue to be a part of the problem or be a part of the solution.

Roberta, a breast cancer survivor of nine years, got involved in NCCS with the support of her mentor and big sister, Sarita. She appreciates NCCS's unique focus on cancer survivorship because it recognizes that life after a cancer diagnosis is never the same.

Throughout Roberta's years of attending CPAT Symposia and NCCS Hill Days, she's enjoyed learning the art of telling her cancer story and urging members of Congress to pass legislation that positively impacts survivors.

“ I go to the Hill because our legislative body needs to be educated on why we're fighting for the things that we're fighting for. They need to understand whatever it is that will help us to continue to survive and live a long, fulfilled life. ”

ROBERTA ALBANY | CPAT MEMBER



STEF GAYHART

Stef Gayhart, a survivor of tongue cancer, participated in NCCS's paid leave campaign. At the time of her diagnosis, she was a 37-year-old single mother who fought for financial independence. She felt extremely fortunate to have health insurance through her employer, but the disability benefits only covered so much. Stef barely made ends meet for well over a year.

When Stef discovered NCCS on social media, she immediately felt that CPAT's mission aligned with her professional and personal goals.

Millions of survivors struggle to balance treatment with the demands of everyday life: finding and affording child care, paying bills, and keeping food on the table. NCCS will continue to elevate the need for a national paid family and medical leave policy as a priority for families like Stef's.

“ I know there are many others like me: young adults just starting their families and careers when the unthinkable hits. That's why I support paid family leave. ”

STEF GAYHART | CPAT MEMBER



Awarding Action

NCCS Presented the 6th annual Ellen L. Stovall Award to Deborah K. Mayer, PhD, RN, and Kimberly D. Richardson for their innovation and dedication to cancer survivors.

The Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care recognizes pioneers who help transform the cancer care system. Named for former NCCS CEO Ellen L. Stovall, who died in 2016 due to cardiac complications from three bouts of cancer, the award highlights those who continue Ellen's work of transforming cancer care to further incorporate patients' goals, needs, and values.

“ Dr. Mayer and Ms. Richardson are incredible leaders who have used their considerable expertise and advocacy skills to improve cancer care and cancer survivorship. They have each dedicated their life's work to advancing science and improving the lives of cancer survivors. NCCS is honored to recognize their efforts with this well-deserved award, named for our former CEO Ellen Stovall. ”

SHELLEY FULD NASSO, MPP | CHIEF EXECUTIVE OFFICER



▶
Deborah
K. Mayer
PhD, RN



◀
Kimberly D.
Richardson

DEBORAH K. MAYER, PHD, RN | RECIPIENT OF THE HEALTH CARE PROVIDER AWARD

A breast cancer survivor herself, Dr. Mayer retired after a distinguished career. She served as the Interim Director of the Office of Cancer Survivorship at the National Cancer Institute (NCI) and is the Frances Hill Fox Distinguished Professor Emeritus of Nursing at the University of North Carolina Chapel Hill School of Nursing. Dr. Mayer is an advanced practice oncology nurse with more than 45 years of cancer nursing practice, education, research, and management experience.

Dr. Mayer is past president of the Oncology Nursing Society, received a presidential appointment to serve on NCI's National Cancer Advisory Board, and was a member of the Board of Scientific Advisors. She is active in the American Society of Clinical Oncology and previously served as Chair of the society's Survivorship Committee.

“ What I find most impressive about Dr. Mayer is how she marries real-world pragmatism with a deep knowledge of both theory and data. Quite simply, she has impeccable judgment with respect to survivorship program development, training initiatives and policy development. Her career-long involvement in cancer care and contributions to survivorship science and care have left Dr. Mayer with a rich and unique perspective on cancer care in this country and around the world. ”

DONALD L. ROSENSTEIN, MD | DIRECTOR, COMPREHENSIVE CANCER SUPPORT PROGRAM,
DIVISION HEAD, GENERAL ADULT PSYCHIATRY, UNIVERSITY OF NORTH CAROLINA AT
CHAPEL HILL

KIMBERLY D. RICHARDSON | RECIPIENT OF THE PATIENT ADVOCATE AWARD

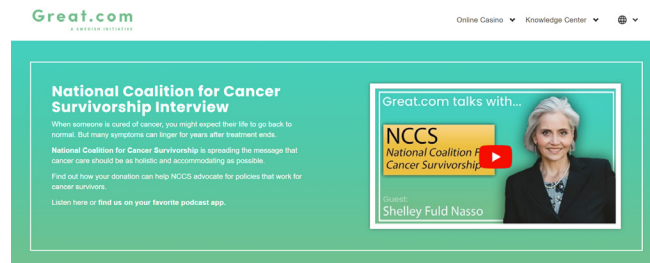
Kimberly D. Richardson, a survivor of both ovarian and breast cancer, was a member of the inaugural group of NCCS Elevate Ambassadors in 2019. The Illinois House of Representatives recently appointed her to serve on the Special Commission on Gynecologic Cancers. Ms. Richardson is the founder and organizer of Chicago's first researcher/survivor summit, newly elected Chair to the Survivorship Committee of the Illinois Comprehensive Care Plan, and Co-Chair of the Patient Advocacy Committee of the Society of Integrative Oncology.

Ms. Richardson is a member of several advisory groups on disparities in ovarian and breast cancer, serves on patient-expert councils for global organizations striving for better outcomes in clinical trials, writes blog posts for the Department of Defense, and advocates at the state and federal level for funding for cancer research.

“ Kimberly is a true champion of the patient perspective with a deep understanding of how all stakeholders interact within cancer communities. She approaches her work with a fierce dedication to honor, integrity, and empathy. Her approach to working with all stakeholders is a master class of diplomacy and collaboration. She understands the problems facing the industry and has a creative and tactful way of navigating some of the toughest conversations around access, equity, and equality for cancer care. ”

ALICIA C. STALEY | VP, PATIENT ENGAGEMENT MEDIDATA

NCCCS in the News



[NCCS CEO Shelley Fuld Nasso Discusses Cancer Survivorship Issues On "Great.com Talks With..." Podcast](#)

"National Coalition for Cancer Survivorship is spreading the message that cancer care should be as holistic and accommodating as possible."

GREAT.COM, JUNE 5, 2021

[Patricia Ganz on how survivorship went from being an outlier to the mainstream](#)

"The National Coalition for Cancer Survivorship began in 1986 with 23 people at a hotel in Albuquerque and a \$100 contribution from Patricia A. Ganz, who recalls thinking: 'I don't think I've ever invested in anything that was so good.'"

CANCER HISTORY PROJECT, NOVEMBER 19, 2021



Penn Medicine

ABRAMSON CANCER CENTER

Finding Purpose Through Her Diagnosis | Sharon's Story
Breast Cancer

[Finding Purpose Through Her Diagnosis | Sharon's Story](#)

"[NCCS CPAT Member] Sharon Rivera-Sanchez never dreamed she'd become a voice for diversity in medical research. But six years after her triple-negative breast cancer diagnosis, the former finance professional has found her calling: Encouraging women of color to take part in clinical trials."

ABRAMSON CANCER CENTER, 2021



[Thirty-five years of advocating for cancer survivors](#)

"The National Coalition for Cancer Survivorship (NCCS) celebrated its 35th anniversary on October 26, 2021 – a day to reflect on nearly four decades of making a difference in the lives of cancer patients and survivors."

CANCER HISTORY PROJECT, OCTOBER 27, 2021

[Desirée A. H. Walker: Empowering Survivors Through Education and Advocacy](#)

"[NCCS CPAT Steering Committee Member] Desirée has provided a patient advocate perspective at the NCCS' Cancer Policy Roundtable, MSK Cancer Center's National Minority Cancer Awareness events, FDA-Duke Accelerating Anticancer Agent Development and Validation (AAADV) Workshops and AACR's 12th Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved Conference to name a few."

AMERICAN ASSOCIATION FOR CANCER RESEARCH, 2021



DESIRÉE A. H. WALKER
Empowering Survivors Through Education and Advocacy



[From Scan to Scan: The Challenges of Living with Metastatic Cancer](#)

[From Scan to Scan: The Challenges of Living with Metastatic Cancer](#)

"We believe there is a need to involve people with advanced disease in research and not just as participants in clinical trials," said [NCCS CPAT Member Christine] Hodgdon."

NATIONAL CANCER INSTITUTE, OCTOBER 15, 2021

[As the War on Cancer Turns 50, Earlier Diagnoses and Treatments Are Saving Lives](#)

"People would whisper the word or call it the 'Big C,' like John Wayne did when he had lung cancer," says Susan Leigh, an oncology nurse and a founding member of the National Coalition for Cancer Survivorship (NCCS)."

AARP, NOVEMBER 4, 2021



[As the War on Cancer Turns 50, Earlier Diagnoses and Treatments Are Saving Lives](#)

A half century since the National Cancer Act passed, understanding of the disease has deepened but challenges remain



WEBMD HEALTH NEWS

[Exercise Gains Traction as a Way to Fight Cancer](#)

[Exercise Gains Traction as a Way to Fight Cancer](#)

"[NCCS CPAT Member Nancy] Howe defied her doctor's orders to rest during cancer treatment, the usual advice in the late 1990s. She kept going to the gym, even if some days, all she could manage was a few minutes on an exercise bike, and she walked around her neighborhood."

JUMPSTART BY WEBMD, DECEMBER 10, 2021

[Disparities In Cancer Survivorship Care](#)

"One such survivor is [NCCS CPAT Member] Woodrow ('Woody'), who experienced health inequity firsthand after being diagnosed with osteosarcoma, or bone cancer, at age nine in the 1960s."

FOX 4, OCTOBER 7, 2021



[Disparities In Cancer Survivorship Care](#)

Support Millions of Cancer Survivors

Your generous contributions enable us to tirelessly advocate for policies that will ensure quality care for all, inform health care professionals about issues important to survivors and those currently in treatment, and support families and caregivers. Your support has an incredible impact on those who rely on NCCS resources from the moment of diagnosis, through treatment, and beyond.

Donor Spotlight

Jeff and Jane Bulman, owners of several Original Pancake House franchises in the DC area, were inspired to begin supporting NCCS through their friendship with former NCCS CEO Ellen L. Stovall. Having learned about Ellen's important work through games of bridge and conversations about cancer survivorship, Jeff and Jane were particularly drawn to her unprecedented focus on the emotional treatment of patients. They understood firsthand how meaningful NCCS's work is to survivors because of their own experience with family members who had cancer. The Bulmans believe it's critical to inform survivors, caregivers, and health care professionals of NCCS resources. "It's so important that other people know this organization exists," Jeff says.

Jane and Ellen spoke every day. As their friendship grew, so did the Bulmans' support of NCCS. Ellen opened their eyes to the value in attending NCCS conferences and workshops, supporting others touched by cancer, and offering resources through NCCS. When Jeff faced cancer, Ellen walked the couple through his diagnosis and treatment.

The Bulmans continue to fulfill Ellen's legacy by making personal gifts and hosting give-back days at their restaurants to benefit NCCS. They want to ensure every survivor has the resources they need to better manage their lives, understand their diagnosis, and improve their wellbeing. "We continue to support NCCS because the work is wonderful, and the word needs to get out on the resources available for both patients and health care providers," Jane says.

“ There are angels in this world that give unconditionally. Jane and Jeff are two of them. The cancer community is continually blessed by their kindness and support. ”

JONATHAN STOVALL | SON OF ELLEN L. STOVALL



◀ Jeff and Jane Bulman

Thank You for Your Generous Donation

WITH YOUR GENEROSITY, WE WILL IMPROVE THE QUALITY OF CARE AND LIFE FOR CANCER SURVIVORS.

Your gift, big or small, will help us improve the lives of cancer survivors. Help us meet the needs of all touched by cancer by visiting www.canceradvocacy.org/donate/ or by mailing a check to NCCS's headquarters at 8455 Colesville Rd. Suite 930, Silver Spring, MD, 20910.

Please consider:

- Making a one-time donation.
- Donating monthly to help fund advocacy and survivor support throughout the year.
- Planning a gift by including NCCS in your will, trust, or estate plans to support our work for years to come.
- Doubling your impact by utilizing your employer's gift matching program.
- Helping others by making a gift in memory of someone dear to you.
- Launching a Facebook fundraiser to share your support of NCCS with loved ones.

For more information, please contact **Director of Development Deborah Lewis at (440) 570-2231** or dlewis@canceradvocacy.org.

INDIVIDUALS

Edith Alger
Suleiman Alibhai
Roselyn Altman
Andrea Anampa-Guzmán
Nardos Aweke
Joyce Bader
Michelle Barnaby
Andrea Becker
Samira Beckwith
Ronald Berenstain
Marjorie and Egon Berg
Zahava Berkowitz
Amy Berman
Sandra Bivens
Douglas and Vicki Blayney
Donna Boss
Sandi Bragin
Susie Brain
Otis Brawley
Cynthia Brenner
Randall Broad
James Brown

Suanna Bruinooge
Jeffrey and Jane Bulman
Nancy Jo Bush
Stuart and Jamie Butler
Darcy Campbell
Jennifer Campisano
Doris Cardwell
Nikki Cheng
Cindy Cisneros
Philip Clesi
Sheila Coffey
Larry Cohen
Michael and Sima Conn
Lorinda Coombs
Kenny Corbin
Dale Cowan
Patrick Coyne
Gail Crawford
Erin Cummings
Michael and
Leslie Cunningham
Bobbi de Cordova-Hanks
Carla De Landri and Fred

Volpacchio
Debora Denardi
Davida Deutsch
Nicole Drost
Suzanne Ducat
Denice Economou
Scottye Edwards
Sofia Farnam
Taylor Ferrell
Sandra Finestone
Benjamin and Julie Fishman
Kathleen Flaherty and
Steve Hantzis
Amy Force
Caren Forsten
Dorie Fournier
Marilyn Frederick
Liza Fues
Jane Fuld
Steve and Jan Fuld
Heather Gaillard
Patricia Ganz
Lisa Garfinkel

Suzanne Gauvreau
Clifton K. Genge
Angelike Giallourakis
Phyllis Gilbert
Dafna Gilboa
Francie Gilman
Sylvia Glaser
Nina Glasner
Lesley Glenn
Betsy Glosik
Judy Goldman
Valerie Goldstein
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Stacey Grayer
Larrie and Joyce Greenberg
Linda Greenberg
Jane and David Greene
Beverly and Stuart Greenfeig
Melinda Griffith
Jim Grigsby
Thomas Guterbock
Alberto Gutierrez

Sheila and Kenneth Handel
Catherine Harvey Sevier and
David Sevier
Susan Heart
Diane Heditsian
Craig Heflinger
Loretta Herring
Holly Hexter
Corinne Hoexter
Barbara Hoffman
Thelma Hoffman
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Marty Holtman
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Stacy Intille
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Patricia Jewell
Debra Johnson
Michael and Kimberly Kappel
Mark Kazich
Page Kennedy and
Mark Rochon
Jay Kenney
Barbara "Cookie" Kerxton
Rebecca Kirch
Karen Kirkland
Shira Klein
Ralph and Lisa Kleinman
Ned Kline
James Knudson
Katharine Kropp
Gordon Krum
Arlene Kutoroff
Stephen Landers
Scott Leader
Colleen Lee
Nita Lee
Susan Leigh
Deborah Lewis
William "Kirby" Lewis
Lifeng Li
Zu-Kei and Yuhlin Lin

Lynn Liston
Ana Maria López
Alexandra Lucy
Glenn Mackles
Vithal Madhira
Jennifer Malin
Deborah Mayer
Mary McCabe
Lora McCann and
Brian Trinkle
Rosemary McHugh
Craig McKay
Tucker Melancon and
Diana Moore
Eileen Miller
Neil and Laura Mitchell
Wyatt and Nancy Moe
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Hayward McDonald
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Carolyn Paget
Mary Paloger
Veronika Panagiotou
Jeffrey Passel
Frances Penan
Marylu Phelan
Linda Piker
Mary Lynn Piven
Susan Plant
Liza Prior Lucy and
William Lucy
John and Connie Raskoske
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Brennan and Helena Reilly
Peter Rez

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Jane Sansbury
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Sarah Scholle
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Dagim Seyoum
Helina Seyoum
Woulita Seyoum and
Ayelework Awoke
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Stephen Lewis
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Robert Young
Lynne Zaklin
Judith Zauderer
Richard Zellars
Barbara Zimmerman
Lorraine Zocchi

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American Society Of
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Bristol-Myers Squibb
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Bulman Enterprises
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David Katz Foundation Inc
Eisai, Inc.
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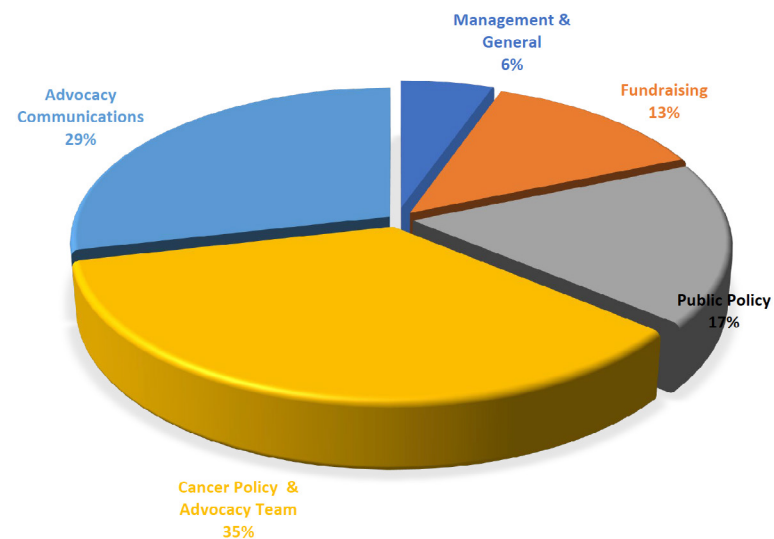


Statement of activities and changes in net assets for the year as of December 31, 2021.

	2021
REVENUE	
TOTAL REVENUE	\$2,130,194
EXPENSES	
TOTAL EXPENSES	\$2,003,571
CHANGE IN NET ASSETS	\$297,839
NET ASSETS (BEGINNING OF YEAR)	\$1,444,103
NET ASSETS (END OF YEAR)	\$1,741,942

The 2021 numbers represented above are preliminary and are subject to change upon audit.

EXPENSES AT A GLANCE



National Coalition for Cancer Survivorship statement of financial position as of December 31, 2021.

	2021
CURRENT ASSETS	
TOTAL CURRENT ASSETS	\$858,692
OTHER ASSETS	
TOTAL OTHER ASSETS	\$1,021,149
TOTAL ASSETS	\$1,879,841
CURRENT LIABILITIES	
TOTAL CURRENT LIABILITIES	\$137,899
NET ASSETS	
TOTAL NET ASSETS	\$1,741,942
TOTAL LIABILITIES AND NET ASSETS	\$1,879,841



NATIONAL COALITION
FOR CANCER SURVIVORSHIP

8455 Colesville Road, Suite 930

Silver Spring, MD 20910

(877) 622-7937

canceradvocacy.org