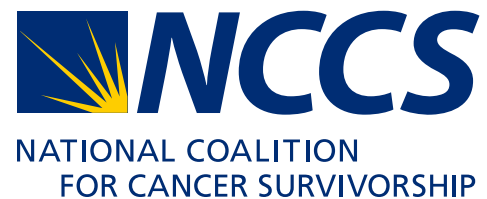


ANNUAL REPORT 2020

# National Coalition for Cancer Survivorship





“  
**We empower survivors  
and impact policy to  
transform health care  
for all people touched  
by cancer.**”

Dear Friends,

2020 was a year none of us will forget. A global pandemic that turned our lives upside down and killed hundreds of thousands of Americans, a national reckoning on racial justice, political polarization and a contentious election. Yet, cancer continued during the pandemic, and cancer survivors had to navigate continuing treatment without family members to accompany them, delays in care, telehealth appointments, and fears about their heightened risks due to their history of cancer.

While the world shut down, our work continued. NCCS quickly pivoted our events to a virtual setting. We hosted our Spring Cancer Policy Roundtable on March 26, 2020, just two weeks after the widespread shutdowns began. Along with everyone else, we quickly learned how to work remotely and to collaborate both internally and with stakeholders across the country.

We responded quickly to the pandemic, hosting webinars and podcasts and sharing resources for cancer survivors about COVID-19. With the explosion in the use of telehealth during the pandemic, we solicited feedback from patients. We conducted focus groups with cancer patients, surveyed providers, and used the feedback to create resources for patients and providers and public policy recommendations.

We advocated for public policies that were important to cancer patients during the pandemic, including access to vaccines and expanded paid family and medical leave to include people with cancer so that cancer survivors could remain home if their job would put their health at risk.

2020 showed us the resilience of cancer patients, who were both vulnerable to the pandemic but also uniquely prepared for it after facing their own health crises. In one podcast episode, I talked with three advocates about their experience living with metastatic cancer during the pandemic. They talked about how they coped with the fear and isolation, as well as how they continued their advocacy during the pandemic. Dr. Kelly Shanahan said, *“I have incurable cancer. When you have a limited lifespan, it’s psychologically challenging to deal with missing out on things.”* Janet Freeman-Daily, a lung cancer advocate, talked about metastatic lung cancer patients who want to spend their limited time making memories with their families. She said, *“You can’t live your entire life locked down when you only have perhaps months to live. It’s a really tough choice.”*

The disparities in COVID-19 outcomes highlighted the huge gaps in our health care system and in health outcomes, which we have long known exist in cancer care. As Dr. Ana Maria Lopez said during a session at our CPAT Symposium in June, *“This pandemic has taken off any band-aid we might have had on health care disparities... The socio-economic impact that we will be seeing in the next couple of years forces us to address equity and access to care.”* NCCS will continue to advocate for public policies that reduce inequities in cancer care.

We could not do any of this work without you, our supporters, or our amazing staff, board of directors, and advocates. Thank you for supporting us through this challenging year and allowing us to continue to work on behalf of cancer survivors and their families.

I am deeply grateful that video conferencing allowed us to stay connected, however imperfectly and despite the “Zoom fatigue” and interruptions from children and barking dogs. Yet, I look forward to the day when we can meet in person again.

Sincerely,

Shelley Fuld Nasso, MPP | Chief Executive Officer



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2020 will be remembered for decades to come for its mix of uncertainty, despair, change, and... hope. Cancer survivors faced a new set of challenges, including an entirely different health care landscape and the fear and anxiety that comes along with isolation. Additionally, COVID-19 unequally affected different racial and ethnic groups, further exacerbating health inequities.

**AND YET, YOUR SUPPORT  
DID NOT WAIVER—  
IT ALLOWED US TO:**

- **Provide guidance** to cancer survivors quickly and efficiently, connecting them with top experts who could answer their questions.
- **Create important resources** to help cancer patients and providers navigate a new environment in cancer care.
- **Advocate for policies** to protect cancer survivors.

**YOUR SUPPORT IS A CATALYST FOR HOPE AND CHANGE.  
THANK YOU.**



# NCCS Mission

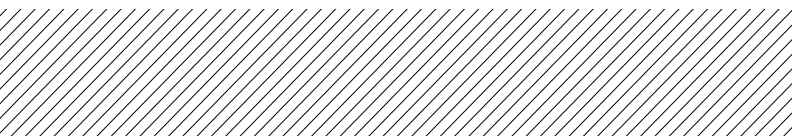
**THE NATIONAL COALITION FOR CANCER SURVIVORSHIP  
CHOOSES HOPE.**

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

At NCCS, we represent the more than 17 million Americans who share a common experience—the survivorship experience—living with, through, and beyond a cancer diagnosis.

The number of cancer survivors in America is equivalent to the population of the fifth largest State in America—bigger than Pennsylvania, Ohio, Georgia, or Michigan. And that number is growing.

**With your support, we give a voice to millions  
of cancer survivors together.**



# State of Cancer Survivorship

## THE PATIENT PERSPECTIVE

We conducted the 2020 State of Cancer Survivorship Survey with a broad, national sample that mirrors the population of cancer survivors in the United States. Consistent themes from the first NCCS survivorship survey in 2018 were identified, such as: cancer survivors face significant challenges both during and after treatment. While the cancer care team effectively addresses many of the physical effects of cancer treatment, survivors reported that their care team is not as helpful addressing other effects of their cancer, including fatigue, anxiety, and depression.

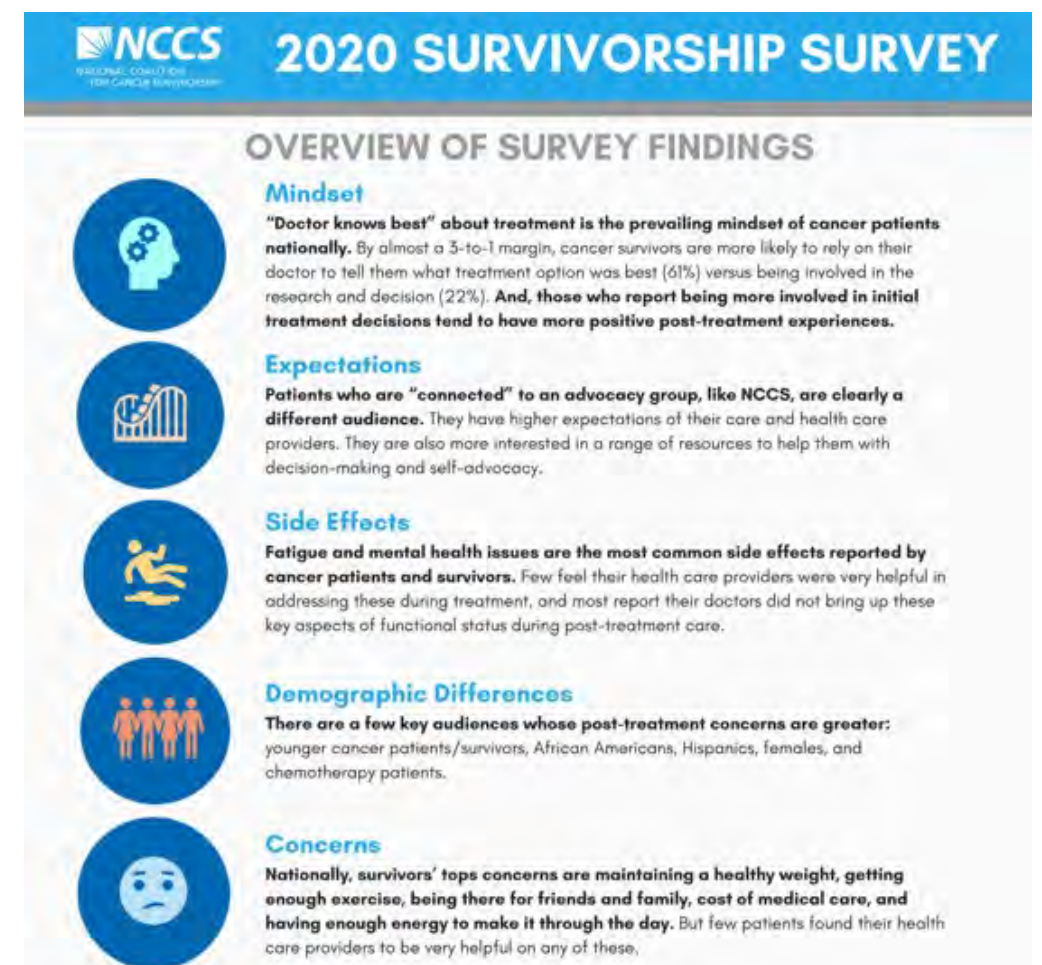
When the national sample is compared with patients who are connected to an advocacy organization, such as NCCS, there are differences in the level of empowerment and involvement in decision-making. The majority of patients in the national sample defer to their clinicians for decision-making about their care, while the engaged patient is more involved in shared decision-making.



**55% of cancer patients who report being involved in treatment decisions felt better prepared for post-treatment.**

*“Educating and empowering patients is an important goal of NCCS, but at the same time, we must work toward a health care system that works for ALL patients, even if they are not able or interested in playing an active role in their care.”*

SHELLEY FULD NASSO, MPP | CEO



READ THE FULL REPORT, EXECUTIVE SUMMARY AND WEB BRIEFING AT [CANCERADVOCACY.ORG/SURVEY2020](https://canceradvocacy.org/survey2020)

# COVID-19 & Cancer Survivorship

**NCCS JUMPED INTO ACTION FOR ALL PEOPLE TOUCHED BY CANCER.**

## **PARTNERING TO MEET THE DEMAND**

We partnered with The American Society of Clinical Oncology (ASCO) to provide expert information on the potential effects of COVID-19 among those diagnosed with cancer. We listened intently to cancer survivors' questions and concerns and provided them with answers to the hard-hitting questions that needed immediate attention.

We found new ways to share timely information with our audience. This included our first NCCS podcast, Cancer Convos. NCCS interviewed health care experts, providers, cancer survivors, caregivers, and advocates about cancer survivorship, advocacy, and policy efforts to improve cancer care in the time of a worldwide pandemic.

**Cancer Convos' topics included:**

- Living with Stage IV Cancer During a Pandemic
- Racial and Ethnic Health Disparities During COVID-19
- Health Policy and Advocacy During the COVID-19 Pandemic
- What Legal and Financial Protections do Cancer Survivors Have During a Pandemic?



**NCCS PODCAST HOSTS HEALTH CARE EXPERTS WHO ADDRESS CORONAVIRUS' IMPACT ON CANCER SURVIVORS.**

Listen to NCCS' podcast, Cancer Convos, for more insights on COVID-19 and its impact on cancer patients and survivors.

[Go to canceradvocacy.org/podcast](https://canceradvocacy.org/podcast)

Last year, we heard from many cancer survivors who felt uniquely vulnerable to the worldwide COVID-19 pandemic due to their history of a cancer diagnosis. Those currently in treatment were worried about delays in care and navigating a stressed health care system.

## **COVERING ALL FACETS OF CANCER CARE DURING A PANDEMIC**

Loss of health care coverage, financial insecurity, fear and anxiety, and questions about the unknown are some of the issues cancer survivors face when there isn't a worldwide pandemic. **Imagine the stress that these issues cause when there IS a worldwide pandemic.**

Our dedicated COVID-19 resources webpage for cancer survivors addressed these topics, and more.

**In addition, NCCS hosted webinars with experts on topics important to cancer patients and survivors:**

- COVID-19 and Cancer: A Conversation with Otis Brawley, MD
- COVID-19 and Cancer: Managing Stress, Anxiety, & Grief with L. Imani Price, PhD
- Radiation Oncology Care during COVID-19, co-hosted with the American Society of Radiation Oncology (ASTRO)





### SHARING CANCER SURVIVORS' PERSPECTIVES ON TELEHEALTH

Telehealth filled a critical gap for cancer care during the COVID-19 pandemic. **Thinking and responding quickly to the rapidly evolving health care landscape, we set out to create resources for both cancer patients and providers.**

We held focus groups with cancer survivors to understand their experiences with telehealth – what worked well and what did not. Additionally, we sought feedback from cancer providers about their use of telehealth. Patients identified the following benefits and drawbacks to telehealth visits:



#### PROS

- Safety during the pandemic, especially for immunocompromised individuals
- Convenience and lower costs associated with travel and time away from work and family
- Reduced barriers for patients with mobility limitations or cognitive deficits
- Ability to record visits and include family/caregivers
- Patients may be more comfortable and less anxious at home
- Providers seem to have more time, fewer distractions



#### CONS

- Technology barriers and anxiety using technology
- Both patient and provider learning curves
- Privacy concerns
- Reduced feelings of connection and emotional support and increased isolation
- Limited access to the cancer care team
- Providers seem to have less time, more distractions

NCCS used this feedback to create tools for patients and health care providers to help maximize the benefits of telehealth.

[LEARN MORE ABOUT THIS PROJECT AT  
CANCERADVOCACY.ORG/TELEHEALTH](https://canceradvocacy.org/telehealth)



#### Project Executive Summary

A summary of the feedback from cancer patients and survivors, including the themes from focus groups, pros and cons for telehealth visits, barriers to telehealth, and planning for the future of telehealth visits.

[View Executive Summary \(PDF\) »](#)



#### For Patients: Tip Sheet for Telehealth Visits (English and Spanish)

A resource for cancer patients and survivors providing advice for scheduling a telehealth visit, completing a technology check, preparing for the telehealth visit, ending the visit and identifying next steps, and providing feedback about the telehealth visit.

[View Patient Tip Sheet \(PDF\) »](#)

[Español Patient Tip Sheet \(PDF\) »](#)



#### For Providers: Cancer Patient Insights Telehealth Recommendations

A resource for oncology clinicians including top-line insights from cancer patients and survivors about their use of telehealth, patient views on the types of visits that are acceptable for telehealth, patient feedback, and recommendations for clinicians.

[View Patient Insights Report \(PDF\) »](#)



# Advocate Spotlight

## Loretta Herring

Communicating electronically became a lifeline this year, but many people lack the technology or skills to participate in virtual meetings, or, more importantly, virtual doctors' visits. Loretta Herring, founder of the Birmingham, Alabama, community organization Cancer Awareness Network, set out to help seniors in her community to use telehealth.

A cancer survivor and NCCS advocate, Herring was a steering committee member for NCCS' Telehealth Project. Loretta wanted to do more — to help Black cancer survivors over age 55 in her local community.

Loretta saw firsthand some of the challenges of virtual meetings in her community. When she called to check on a friend who missed a group Zoom meeting, her friend said, *"I don't know what Zoom is."* She found this technology barrier to be a common theme. Loretta once referred to a computer mouse when speaking to an 80-year-old cancer survivor, who exclaimed, *"I don't have mice in my house!"*

### COMPASSION AND PATIENCE

Building on her experience with NCCS, Herring created Project Telehealth to assist seniors with technology for telehealth visits. She trained a group of telehealth educators on technology and safety standards, and how to support seniors with compassion and patience.

Loretta says the pilot has helped patients attend their telehealth visits and make the most out of them. Patients will often log in early to their appointments with prepared questions and notes, in addition to checking their blood pressure or other vital signs in advance of the visit.

Unfortunately, not every patient has access to the technology needed for telehealth visits. Loretta was able to provide some patients with a tablet to use during the pilot and is currently seeking funding to expand the project's resources.



▲  
NCCS advocate and cancer survivor,  
Loretta Herring

*Loretta witnessed some of the challenges of virtual meetings in her community. Loretta once referred to a computer mouse when speaking to an 80-year-old cancer survivor, who exclaimed, "I don't have mice in my house!" She found this technology barrier to be a common theme.*



# Veronika Panagiotou, PhD

Before the pandemic, Non-Hodgkin Lymphoma survivor Veronika Panagiotou, PhD was one of the first faces that visitors to the Children's Museum of Pittsburgh saw. She loved her job and her connection with the children. When the pandemic began and the museum closed to visitors, Veronika was furloughed from her position and safely quarantined at home. When her employer contemplated re-opening, Veronika had limited options for her well-being and compromised immune system.

*“Do I lose my salaried job that I love, which gives me the health benefits I need as a cancer survivor, or do I keep my job and risk contracting COVID-19, which could kill me?”*

VERONIKA

As Congress was considering COVID-19 relief packages in the summer of 2020, NCCS called on Congress to ensure people with underlying health conditions and working members of their household would receive job protection and financial support to enable them to remain at home during the pandemic.

Veronika shared her story in support of our advocacy on this issue, including in several advocacy action alerts, the NCCS Cancer Convos podcast, social media, and dedicated emails to the NCCS audience. She was willing to share her life with people she didn't know so, together, we could highlight the importance of expanded paid family leave.





# Impacting Policy

For nearly three decades, NCCS has advocated for public policies to improve cancer care for all cancer survivors. 2020 was particularly challenging for cancer survivors, due to their potential increased risk of contracting COVID-19. NCCS immediately focused our policy efforts on the needs of cancer survivors during the pandemic, while continuing to advocate for improved cancer care for all those touched by the disease. Our policy priorities for 2020 included:

## Supporting Access to Affordable, Quality Healthcare

Cancer survivors rely on access to quality, affordable health care. NCCS supports and defends the Affordable Care Act (ACA), including its expansion in access to care and essential patient protections. NCCS also shared the cancer patient perspective in drug pricing proposals.

### HERE'S HOW NCCS SUPPORTED PATIENT ACCESS TO CARE IN 2020:

- NCCS joined patient groups in amicus briefs to the Supreme Court for several cases with important implications for cancer survivors, including Texas v. US, in which the groups supported upholding the ACA. Another brief challenged rules on short-term, limited duration insurance plans, while a third brief challenged a rule that allows discrimination in health care services against gay and transgender individuals.
- NCCS joined patient and consumer groups in a letter urging the Administration to implement a special enrollment period for healthcare.gov during the COVID-19 pandemic.
- NCCS urged the Centers for Medicare and Medicaid Services (CMS) to withdraw the Most Favored Nation (MFN) Medicare Part B Rule, which could restrict access to life-saving treatments for cancer survivors.
- NCCS submitted comments to the Health and Human Services Department opposing changes to the six protected classes in Medicare Part D, as the elimination of protected classes policy would deny patients access to necessary medications.

## Driving Patient-Centered, Value-Based Care

NCCS advocates for patient-centered payment, which includes shared-decision making, evidence-based care, and patient-reported outcome measures.

### HERE'S HOW NCCS ADVOCATED FOR CANCER SURVIVORS IN PAYMENT REFORM EFFORTS:

- NCCS submitted recommendations to CMS regarding Proposed 2021 Hospital Outpatient Prospective Payment System.
- NCCS submitted comments regarding a proposed Social Security and Disability Income (SSDI) Regulatory Review Rule that would impose unnecessary burdens on cancer survivors who rely on SSDI.
- NCCS submitted comments to CMS regarding payment policies that would impact cancer survivors under the Physician Fee Schedule.

◀ NCCS CEO Shelley Fuld Nasso joins patient advocates and cancer survivors on Capitol Hill to advocate for quality cancer care.







◀ Experts discuss health equity in cancer care at the Fall 2020 CPR.

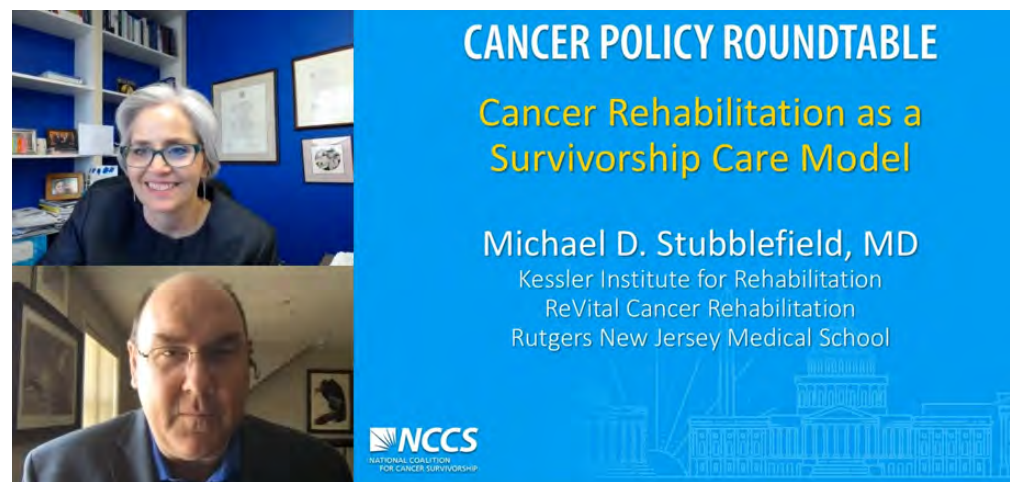
Clockwise from top-left:  
Arnethea L. Sutton, PhD;  
Nadine J. Barrett, PhD;  
Otis Brawley, MD; Katherine E.  
Reeder-Hayes, MD

### ADVOCATING FOR CANCER SURVIVORS DURING THE COVID-19 PANDEMIC

Through legislative and regulatory efforts, NCCS advocated on behalf of cancer survivors who are at increased risk of complications from contracting the COVID-19 virus.

#### HERE'S HOW NCCS ADVOCATED FOR CANCER SURVIVORS DURING THE PANDEMIC:

- NCCS submitted a comment letter to the National Academy of Medicine on the COVID-19 vaccine panel's vaccine allocation plan draft, urging the panel to prioritize cancer survivors for the vaccine in Phase 1B.
- NCCS submitted a letter to Senator Lamar Alexander (R-TN) recommending that the COVID-19 Medicare Telehealth Coverage Expansion be made permanent.
- NCCS urged Congress to include cancer survivors in the expansion of paid family and medical leave through the pandemic.



### 20TH YEAR OF CANCER POLICY ROUNDTABLES

NCCS hosted our 20th year of semi-annual Cancer Policy Roundtable “think tank” meetings, bringing together providers, researchers, advocates, and policy makers to discuss the latest in cancer care and policy. This year we held our first-ever virtual roundtable, as we quickly converted our plans for the March 2020 roundtable when the pandemic began. We convened top experts to discuss the future of cancer care, while the current health care landscape was rapidly evolving.

### 2020 SPRING CANCER POLICY ROUNDTABLE

Dr. Otis Brawley set the stage for the spring event by providing context for the future of cancer care in the next decade. We also welcomed patient advocates, family caregivers, and health care experts who discussed end-of-life care and needed policy changes. Lisa Rice, NCCS board member and panelist, shared that her chief lesson in caring for loved ones at the end of the life is that early conversations are so important. **“Conversations early on are critical, so that you can make good decisions with them (patients) - or in some cases - on behalf of them.”** Other topics included cancer rehabilitation as a model of survivorship care and the Oncology Care Model and proposed Oncology Care First model.

### 2020 FALL CANCER POLICY ROUNDTABLE

With the presidential election on the top of our minds, we began our fall roundtable with a lively and informative discussion on what the results of the election mean for health policy in 2021. We also discussed the pressing inequities of the health care system, which disproportionately hurts patients of color, and potential solutions. We ended the 20th annual year of Cancer Policy Roundtables with the new era of patient access to care: telehealth.

*“Equality is not just achieved by equitable treatment, although that’s where our focus often lies. It is important to ensure everyone has access to prevention, screening, and diagnosis as well”*

OTIS BRAWLEY, MD

LEARN MORE ABOUT OUR POLICY ROUNDTABLES AT [CANCERADVOCACY.ORG/CPR](https://canceradvocacy.org/cpr)

# Empowering Advocates

## THE 7TH ANNUAL CANCER POLICY & ADVOCACY TEAM (CPAT) SYMPOSIUM AND HILL WEEK

Advocates from across the country attended our first-ever virtual CPAT Symposium and Hill Week. The virtual setting allowed more advocates to participate, and we had record attendance. 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 everyone.

Advocates learned from renowned experts, heard from all-star advocates, and leveraged their personal stories to improve cancer care. Whether a brand-new advocate or seasoned Symposium attendee, attendees chose their own adventure to help find their voice, or fine-tune it.



**WOODROW BROKENBURR, MBA**

NCCS Elevate Ambassador Woodrow (Woody) Brokenburr, MBA, is a long-term cancer survivor who has spent the majority of his life actively advocating for cancer survivors. Woody is passionate about cancer research and connecting scientists with those who have been touched by cancer.

Woody presented on “Overcoming Health Disparities and Access to Breast Cancer Care” for the Los Robles Health System’s Power of Pink: 24th Annual Breast Cancer Awareness Month.



**NANCY HOWE**

NCCS Elevate Ambassador Nancy Howe met her aggressive cancer treatment with her guiding light: being physically active. Instead of resting, she focused on moving as much as the side-effects of her treatment would allow. Now she advocates for access to cancer rehabilitation services to help cancer survivors maintain the highest possible level of function and quality of life.

Nancy shared her personal experience with *Conquer Magazine*, in which she wrote about the power of advocacy and using one’s voice, as well as the benefits of cancer rehabilitation.

*“If my story offers any advice, it is to echo the words of so many—that volunteering is healing, and that joining a larger cause ends isolation.”*



#### CONTINUING TO ELEVATE SURVIVORSHIP

In the second year of our Elevating Survivorship (Elevate) initiative, NCCS continued to empower and support Elevate Ambassadors in their unique projects to improve survivorship care at the local level.

Who better to help shape opportunities to improve survivorship care than survivors themselves?

#### PAVING THE WAY FOR MUCH-NEEDED COMMUNITY CANCER CARE

Through a competitive application process, NCCS selected 13 new Elevate Ambassadors in 2020.

#### 2020 AMBASSADORS:

JOLI BARTELL, Washington

WOODROW BROKENBURR, California

JENNIFER CAMPISANO, Arizona

CRYSTAL CHAMPION, Georgia

LESLEY GLENN, Oregon

KIMBERLY HARRISON, Maryland

NANCY HOWE, Arizona

WENORA JOHNSON, Illinois

JOSLYN MCARDLE, New York

DEBBIE DENARDI (SETUAIN), Florida

AMY OLIVER STEINKUHL, Kentucky

SUSAN STRONG, Colorado

CHRISTI TURNAGE, Mississippi



*"I would never have even attempted something like this without the support and encouragement of NCCS. It's been a game changer and a life changer as well."*

*"Not really knowing anything about NCCS before applying, I found the Elevating Survivorship program to be extremely supportive, inclusive, and enlightening. Meeting so many smart, talented, driven advocates was very inspiring."*

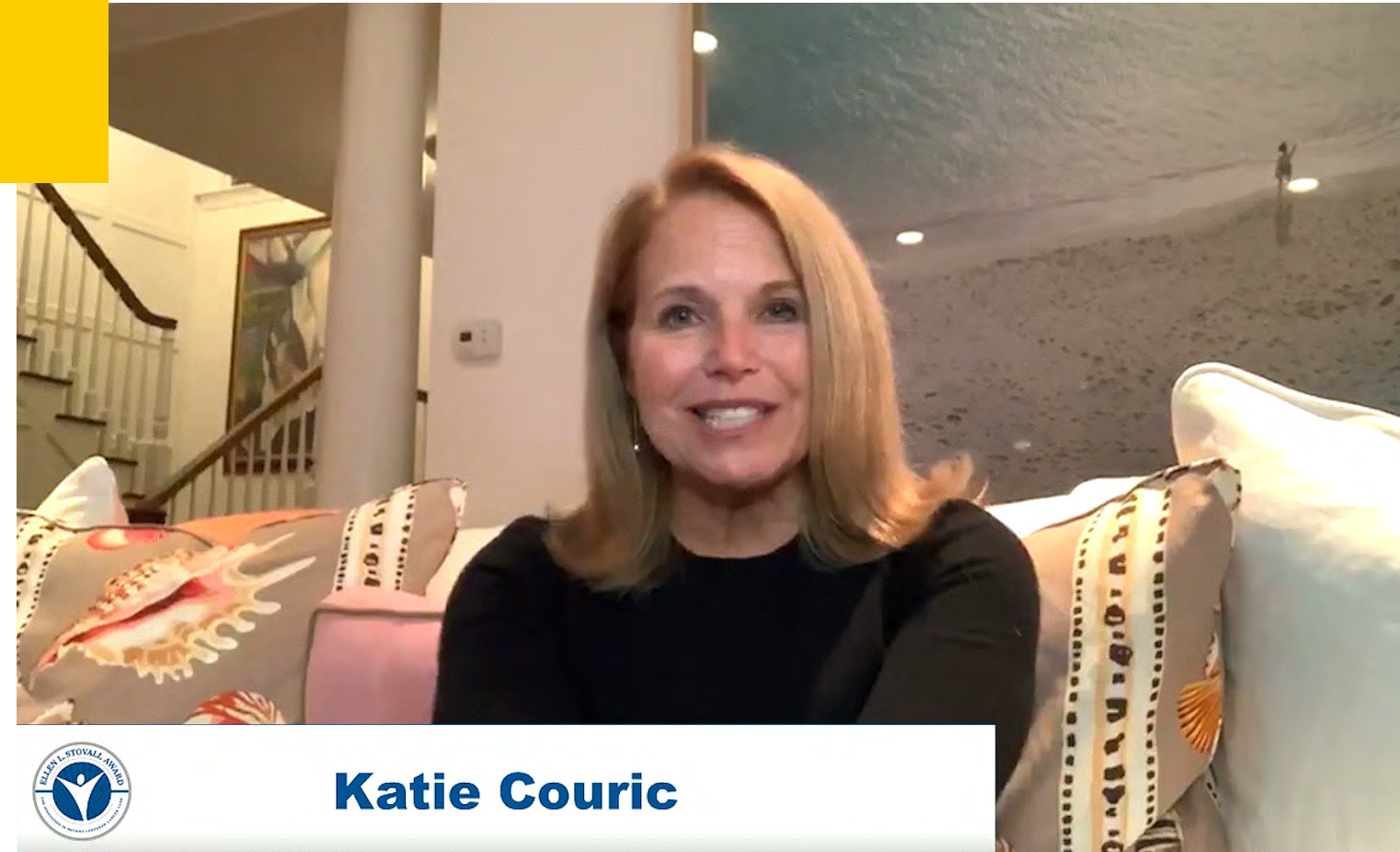


# Honoring Leaders

NCCS PRESENTS 5TH ANNUAL ELLEN L. STOVALL AWARD TO JULIA H. ROWLAND, PHD AND THOMAS J. SMITH, MD FOR THEIR INNOVATION AND DEDICATION TO CANCER SURVIVORS

The Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care recognizes pioneers who are transforming the cancer care system. Named for former NCCS CEO Ellen 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.

The virtual award reception began with a video message from award-winning journalist Katie Couric and included a conversation between Shelley Fuld Nasso and Congressman Jamie Raskin (D-MD). Congresswoman Eleanor Holmes Norton (D-DC) joined NCCS to present the award to her constituent, Julia H. Rowland, Ph.D., and Senator Chris Van Hollen (D-MD) presented the award to his constituent, Thomas J. Smith, MD.



**Katie Couric**

*"It was Ellen who gracefully taught us to choose hope. It is fitting that we honored her legacy at the 2020 Stovall Awards Reception during this unprecedented time when we all need to continue choosing hope. The 2020 Stovall Awards Reception is, without a doubt, the most important night of NCCS' year. The winners exemplify her life's work and passion. We are deeply grateful to Dr. Rowland and Dr. Smith for dedicating their careers to improving cancer care."*

SHELLEY FULD NASSO, CEO, NCCS.





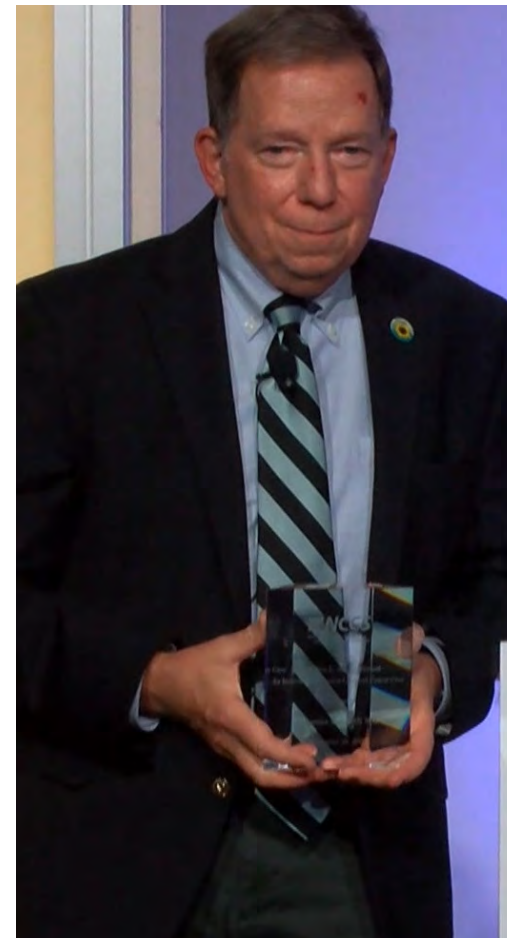
#### JULIA ROWLAND, PHD

Dr. Rowland is a long-time clinician, researcher, and teacher in the area of psychosocial aspects of cancer. She has worked with and conducted competitively funded research among both pediatric and adult cancer survivors and published broadly in psycho-oncology.

She was recruited to the National Cancer Institute (NCI) to become the first, full-time Director of the Office of Cancer Survivorship (OCS). After 18 years in this role, Dr. Rowland retired from service at the NCI in September 2017 and assumed the role of Senior Strategic Advisor at Smith Center for Healing and the Arts, a small non-profit organization that has been providing integrative support services to cancer patients and their families for over twenty years.

*“Across her career as a clinician, researcher, and teacher in the area of psychosocial aspects of cancer, Dr. Rowland has promoted patient-centeredness, engaged patients, families, and caregivers to inform the process of improving the delivery of quality cancer care and collaborated effectively with others to improve quality within the cancer care system”*

DR. DEBORAH K. MAYER, PHD, RN, WHO NOMINATED DR. ROWLAND.



#### THOMAS J. SMITH, MD

Dr. Smith is a professor of oncology at the Johns Hopkins University School of Medicine, director of Palliative Medicine for Johns Hopkins Medicine and the Harry J. Duffey Family Professor of Palliative Care. He is a medical oncologist and a palliative care specialist with a lifelong interest in better symptom management, communication, and improving access to high quality affordable care. Dr. Smith began Johns Hopkins' hospital-wide palliative care consult service as well as an inpatient unit, and he is dedicated to accelerating palliative care research and education.

Dr. Smith is also a prostate cancer survivor, experiencing first-hand surgery, recurrence, radiation therapy and androgen deprivation therapy with many significant side effects. He knows all too well the experience of living and continuing to work with cancer.

*“Dr. Smith provides total and compassionate care to improve the quality of life of all suffering from their illness. He creates a calm environment which is unhurried, allowing the patient to be empowered to have critical conversations. Dr. Smith has taught hundreds how to improve their own skills and thereby the quality of care they deliver”*

PATRICK. J. COYNE, MSN, RN, WHO NOMINATED DR. SMITH

# In Memoriam

## Elizabeth “Betsy” Clark, PhD

Dr. Elizabeth “Betsy” Clark passed away on May 23, 2020. Betsy was a true champion for cancer survivors. Her leadership, service, and contributions to NCCS and the field of cancer survivorship were vast. She was formerly Executive Vice President of NCCS, and the Chief Operating Officer for THE MARCH...Coming Together to Conquer Cancer, which culminated in a national rally in Washington, DC in September 1998 that brought more than 100,000 supporters to the National Mall.

She was the author or co-author of many NCCS publications and resources, such as the Cancer Survival Toolbox; Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability; You Have the Right to be Hopeful; Teamwork: The Cancer Patient’s Guide To Talking With Your Doctor; Self-Advocacy: A Cancer Survivor’s Handbook; and many others.

A social worker, she was the longtime CEO of the National Association of Social Workers from 2001-2013 and a board member of numerous non-profit organizations. Betsy described herself as a “hope advocate” after hearing from cancer survivors about their experiences. Her most recent book, published in 2017, was entitled Choose Hope (Always Choose Hope). A quote from her book:

*“Hope is powerful—more powerful than fear or despair or even grief. Your hope always stands waiting, ready to help you cope and move forward. No matter how difficult or dire the situation, hope is possible and necessary. Never give in to hopelessness. Instead, choose hope. Always choose hope.”*







# Kathy LaTour

**Kathy LaTour, breast cancer survivor, author of *The Breast Cancer Companion*, and co-founder of CURE Magazine, died on June 19, 2020. Kathy served as an NCCS board member from 1992 to 1996.**

**After her cancer diagnosis in 1986, she turned her formidable writing talents to informing and supporting cancer patients and survivors.**

In 1992, Kathy joined the NCCS board and quickly assumed the role of Communications Chair. In a blog post last year, Kathy talked about being an advocate and her involvement with NCCS, including her participation in the THE MARCH...Coming Together to Conquer Cancer, which brought 100,000 people to Washington, DC in 1998.

She said that her involvement with NCCS opened her eyes to see the role of non-profit advocacy groups to make a difference and inspired her, along with colleagues, to be a founding member of The Bridge Breast Network, which provides diagnostic and treatment services to low-income and uninsured people with breast cancer in North Texas.

In a tribute shared on CURE's website, Dr. Debu Tripathy, CURE's editor-in-chief, said, "Kathy was always in command — she reminded us of both the frailties as well as the strength and resolve of cancer survivors in very special ways through storytelling and memorable one-liners."

# NCCS in the News

## THE CANCER LETTER

### CLINICAL ROUNDUP

## NCCS survivorship data demonstrates prevailing “doctor knows best” mindset

September 04, 2020 | Vol.46 No.33

“NCCS SURVIVORSHIP DATA DEMONSTRATES PREVAILING ‘DOCTOR KNOWS BEST’ MINDSET”

THE CANCER LETTER, SEPTEMBER 4, 2020

“NEW SURVEY REVEALS CANCER SURVIVORS’ ATTITUDES TO CARE, UNMET NEEDS”

ONCOLOGY TIMES, SEPTEMBER 5, 2020

oncolology-times.com  
**ONCOLOGY TIMES**  
Independent News on  
HEMATOLOGY / ONCOLOGY

“THE BEST RESOURCES FOR COPING WITH CORONAVIRUS AND CANCER”

CANCER HEALTH, APRIL 7, 2020

## Cancer Health™



“FOR CANCER PATIENTS, PANDEMIC BRINGS NEW HURDLES IN AND OUT OF TREATMENT”

CLEAR HEALTH COSTS, JULY 16, 2020

## OncLive®

“EMOTIONAL AES REMAIN A BLINDSPOT IN ONCOLOGY CARE”

ONCLIVE, OCTOBER 6, 2020

“MY CANCER SURVIVOR STORY AND THE POWER OF YOUR UNIQUE VOICE”

CONQUER MAGAZINE, AUGUST 2020

## CONQUER™

the patient voice™

“ONGOING MINORITY UNDERREPRESENTATION IN CLINICAL RESEARCH LEADS TO EFFORTS TO BRIDGE THE DIVIDE”

TARGETED ONCOLOGY, SEPTEMBER 2020

## Targeted Oncology™

healthline Learning Center Wellness Planning Community  
HEALTH NEWS ✓ Fact Checked  
The Emotional Trauma Felt by Shannen Doherty and Others When Their Cancer Returns



“THE EMOTIONAL TRAUMA FELT BY SHANNEN DOHERTY AND OTHERS WHEN THEIR CANCER RETURNS”

HEALTHLINE, FEBRUARY 11, 2020



# Financials

Statement of activities and changes in net assets for the year as of December 31, 2020.

	2020
REVENUE	
TOTAL REVENUE	\$1,582,819
EXPENSES	
TOTAL EXPENSES	\$1,479,240
CHANGE IN NET ASSETS	\$142,598
NET ASSETS (BEGINNING OF YEAR)	\$716,099
NET ASSETS (END OF YEAR)	\$858,697

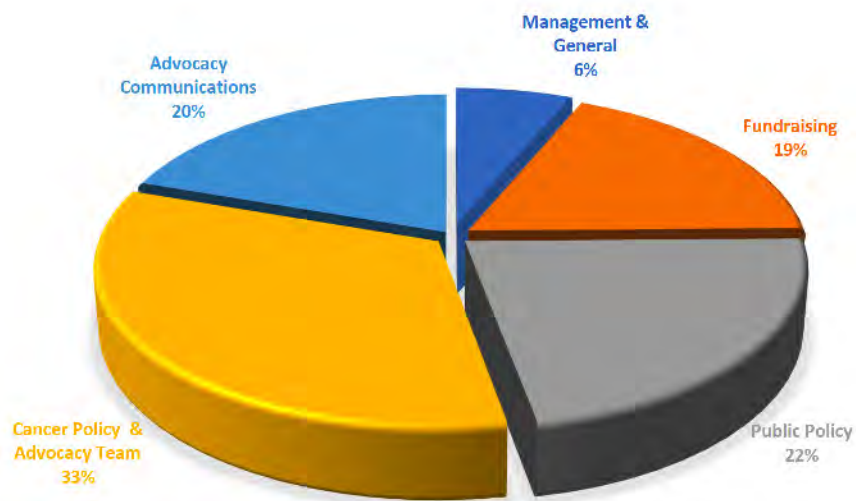
The 2020 numbers represented above are preliminary and are subject to change upon audit.



National Coalition for Cancer Survivorship statement of financial position as of December 31, 2020.

	2020
CURRENT ASSETS	
TOTAL CURRENT ASSETS	\$615,295
OTHER ASSETS	
TOTAL OTHER ASSETS	\$836,008
TOTAL ASSETS	\$1,451,303
CURRENT LIABILITIES	
TOTAL CURRENT LIABILITIES	\$279,398
NET ASSETS	
TOTAL NET ASSETS	\$1,171,905
TOTAL LIABILITIES AND NET ASSETS	\$1,451,303

## EXPENSES AT A GLANCE



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