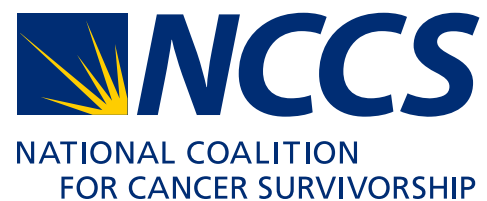


ANNUAL REPORT 2019

# National Coalition for Cancer Survivorship





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

Dear Friends,

Throughout 2019, The National Coalition for Cancer Survivorship (NCCS) empowered cancer survivors to receive the resources, opportunities, connections, and inspiration they need to help improve cancer care. In addition to advocating on behalf of survivors, we implemented new programs and initiatives that enabled survivors to pave the way for better care.

In early 2019, NCCS disseminated the results of our nationwide survivorship study to address areas for improvement in cancer care. We heard from survivors that their biggest concerns are dealing with fatigue and anxiety during and after treatment. Additionally, survivors feel that while health care teams manage physical side effects, like nausea and vomiting, they are not adequately addressing the survivors' top priorities: anxiety, depression, fatigue, and cognitive effects. Few survivors feel very prepared for the transition to post-treatment, nor informed about how to manage their health post-treatment.

We shared the survey results widely and garnered media coverage of what we learned. Survivors' needs continue to inform everything we do at NCCS, including the following projects and initiatives:

- NCCS successfully launched [“Elevating Survivorship”](#) (also known as Elevate), a patient- and advocate-led initiative to improve survivorship care at the local level and in communities.
- NCCS put survivors in the driver's seat to [define quality measurements](#) by convening a group of survivors to define what living well with and after cancer means to them and how the health care system should support them.
- NCCS convened policy meetings with experts to assess the health care landscape and cancer policy issues so we could effectively represent survivors' needs.
- NCCS created the [Cancer Survivorship Checklist](#), a simple straightforward tool patients and caregivers can use as a guide for information critical to their care wherever they are on the cancer care continuum.
- NCCS hosted an [annual symposium](#) for survivors and caregivers to provide the education, inspiration and tools they need to be strong advocates for themselves and for other cancer survivors.

The nearly 17 million cancer survivors in the United States fuel our work every day by motivating and inspiring us. We are deeply grateful for the hundreds of advocates who work tirelessly with NCCS to support their fellow survivors and for the donors and partners who supported our efforts.

**Thank you to everyone who worked with NCCS to make cancer survivors' voices heard in 2019.**

Sincerely,

A handwritten signature in yellow ink that reads "Shelley". The signature is fluid and cursive, written in a professional yet personal style.

Shelley Fuld Nasso, MPP  
Chief Executive Officer

**NCCS' MISSION IS TO ADVOCATE FOR QUALITY CANCER CARE FOR ALL PEOPLE TOUCHED BY CANCER.**

**NCCS believes the cancer survivorship experience can be a transforming, positive force, yet also recognizes that cancer survivors and those who care for them face many challenges. That's why we advocate for quality cancer care for all people touched by cancer. Founded by and for cancer survivors, NCCS created the widely accepted definition of survivorship and defines someone as a cancer survivor from the time of diagnosis and for the balance of life.**

**IN 2019, YOUR SUPPORT HELPED NCCS:**



**Advocate for change** in how the nation researches, regulates, finances, and delivers quality cancer care.



**Empower cancer survivors** through its publications and programs, which provide tools for self-advocacy.



**Convene advocates and experts** to address national public policy issues affecting cancer survivors.

**TABLE OF CONTENTS**

**02** Letter from CEO

**03** NCCS' Mission and Table of Contents

**04** Spotlight on NCCS Founding Member, Fitzhugh Mullan, MD

**05** Survivor Spotlights

**07** Policy Priorities

**08** Transforming Care

**10** Impacting Policy

**11** Promoting Advocacy

**13** NCCS in the News

**14** Financials

**15** Supporters

**16** Policy Advisors, NCCS Board Members & Staff

Thanks to your continued support, NCCS advocates for the nearly 17 million cancer survivors in the United States.

## REMEMBERING

# Fitzhugh Mullan, MD



It is with profound sadness that we acknowledge the death of Fitzhugh Mullan (Fitz), MD, the co-founder and first president of NCCS on November 29, 2019. With dignity, kindness, brilliance, and selfless energy, Fitz built the foundation upon which NCCS rests today. His work has enhanced the lives of countless cancer survivors through advocacy for their medical, emotional, financial, and social needs, from the moment of diagnosis through the balance of their lives.

As a young physician in 1975, Fitz was diagnosed with cancer at a time a cancer diagnosis was commonly a death sentence, often kept secret from friends, family, and coworkers.

Always an activist for the rights of the disadvantaged, ten years after his own cancer experience, Fitz wrote “Seasons of Survival, Reflections of a Physician with Cancer,” a transformative piece published in the *New England Journal of Medicine* that served as a catalyst for the modern cancer survivorship movement. He generously shared his cancer experience as a badge of honor and fought for a better quality of life for all survivors.

In October 1986, Fitz and Catherine Logan, Executive Director of Living through Cancer — a support center for patients and families dealing with cancer — led a weekend retreat in Albuquerque, New Mexico, of survivors and caregivers to build a movement of and for cancer survivors.

He deftly shepherded a room full of strangers in one short weekend into a collaborative group dedicated to changing the landscape for cancer survivors. Fitz led the discussion that redefined the lexicon of cancer including, importantly, what it meant to be a cancer “survivor,” and founded NCCS.

We are here today because of the audacity and vision Fitz created for NCCS. We mourn the passing of our dear friend, mentor, and beloved colleague.

**ADAPTED FROM A BLOG POST WRITTEN BY BARBARA HOFFMAN, SUSIE LEIGH, AND JULIA ROWLAND**

*Barbara Hoffman, JD, and Susie Leigh, BS, RN, are co-founders of NCCS and were present for the first meeting in Albuquerque, NM 33 years ago.*

*Julia Rowland, PhD, is currently an NCCS board member and was director of the National Cancer Institute's Office of Cancer Survivorship for nearly 20 years.*

# Survivor Spotlight



## Heidi Floyd

### INSPIRING FUTURE GENERATIONS

Over 15 years ago, Heidi Floyd was advised by countless doctors to terminate her pregnancy when she was diagnosed with breast cancer. She would not allow the diagnosis, which took her mother's life, to also seal the fate of her unborn baby boy. That is why she packed up her family every weekend to stay in another state's hotel for treatments with a doctor that gave her and her baby the chance to live.

Heidi's teenage daughter, Catie, remembers those days on the road vividly. The memories of her mom fighting for her life, and her brother's, shaped who she is now. Bright and courageous, Catie researches the lawmakers who advocate for quality cancer care and refers to her local officials with ownership, saying, "my representative." She knows who the lawmakers are, what they stand for, and even better – she knows what she stands for.

Catie accompanied Heidi to NCCS' Cancer Policy and Advocacy Team (CPAT) annual symposium and found her own voice as an advocate. It was no surprise that when she was stopped in the halls of Capitol Hill by countless lawmakers, or when she was randomly chosen from a large crowd by Speaker Pelosi to stand beside her, she faced it with fearless enthusiasm.

The future is full of hope, and Heidi,  
alongside her family, advocate for a better one.

# Advocate Spotlight

## Virgie Townsend

### STRENGTH COMES FROM OUR ADVOCATES

**Virgie Townsend learned about her 19-year-old son's cancer recurrence, which had a 10% survival rate, over the phone. A modest and graceful woman, she found this life-altering, informal exchange to be one of the hardest moments of her son's cancer journey. Although her son Martin, and the rest of the world, would never know anything bothered Virgie, she gave her son relentless faith, encouragement, hope, and fuel that he held firmly during treatments.**

Just like mother and son, Martin's recurring cancer was relentless. Yet, it exhausted Virgie to think about the time, energy, and worry this diagnosis required. It's one of the reasons Martin and Virgie flew to a gaming conference in Las Vegas, by donation, prior to the beginning of his treatments. Cancer may demand a lot - but Virgie and Martin were determined not to let cancer rob them of joy and memories.

Intelligent and optimistic, Martin shared his experience at NCCS' annual CPAT symposium while Virgie smiled with pride. The entire room of cancer survivors and advocates felt his joy, optimism, and strength. Virgie and Martin planted seeds of inspiration by making a crowd with heavy burdens feel lighter.

Virgie and Martin believe in the importance of community - which is why they advocate.



# Policy Priorities



**NCCS works to improve and personalize the delivery of cancer care from the moment of diagnosis through the balance of life. In order to do so, we focus our efforts on several key policy priorities, which include:**

**Care planning and coordination** – All patients should receive treatment and survivorship care plans, which are comprehensive, lay out critical components of care, and are reviewed with patients and caregivers. Patients have enough to worry about when facing cancer and coordinating their care between numerous providers shouldn't be one of them.

**Access to affordable, quality healthcare** – Before the passage of the Affordable Care Act (ACA) in 2010, cancer patients faced many barriers to quality health care, including: being denied insurance because of pre-existing conditions, out-of-pocket expenses that could land them in debt, and fewer treatment options. We can never go back to a system that discriminated against cancer survivors and their families. That is why NCCS is an outspoken leader to defend the ACA and its critical patient protections and expansion of access to care.

**Care that incorporates patients' goals and values** – The standard of care must go beyond just diagnosis and treatment of the cancer. It must include substantive doctor-patient communication to incorporate patients' goals and values when discussing all decisions throughout the cancer care continuum.

**Payment reforms to drive patient-centered, value-based care** – As our country moves away from the current fee-for-service system, which rewards providers based on the quantity of care rather than quality of care, NCCS advocates for patient-centered payment that includes shared-decision making, evidence-based care, and patient-reported outcome measures.

**High-quality review to ensure safe and effective cancer drugs reach patients** – NCCS ensures that the Food and Drug Administration (FDA) has the resources and protocols in place to substantively review cancer treatments for safety and efficacy, while being able to bring new treatments to patients as quickly as possible.

# Transforming Care

## ASSESSING AND IMPROVING CANCER SURVIVORS' FUNCTIONAL STATUS

**NCCS received a grant from the American Institutes for Research (AIR), with support from the Robert Wood Johnson Foundation, to lead a group of cancer survivors in defining a new quality measure concept to represent cancer survivors' ability to return to functional status (RFS) following cancer treatment. This grant process was highly competitive, and NCCS was the only patient advocacy organization selected.**

One of the project's main consensus recommendations was a core requirement that cancer providers conduct routine functional status assessment during and after treatment. Unfortunately, the RFS Committee consensus and published literature indicate that standard assessment of these domains is the exception, rather than the norm, in cancer care today. The process measures help specify the current performance gap and highlight initial opportunities for improvement.

The committee also concluded that an RFS measure set must evaluate providers' reaction to any poor or concerning patient responses to any administered survey. Thus, the final measure set also includes a group of process measures regarding provider action taken, as needed.

Finally, the committee prioritized inclusion of measures regarding side effects and late effects of cancer treatment, as well as the financial impacts of cancer. The group determined that measurement is best focused on the quality of provider communications and information sharing.

## KEY FINDINGS

Committee members concluded that "functional status" was important and conveyed something different and more specific than a general term like "quality of life." They did not like the idea of "returning" to something because the reality of cancer is that life is never the same after a cancer diagnosis.

The committee decided on "redefining," because it acknowledges that patients and the health care team have an active role in determining functional status after a cancer diagnosis. This small but important change indicates active engagement during the cancer trajectory to prepare patients for changes and in managing functional status impacts.

## PRIORITIZED OUTCOME MEASURES:

- Global quality of life (including overall physical and mental health)
- Physical function
- Pain
- Fatigue
- Cognitive function
- Psychosocial illness impact (including emotional problems, depression, independence, sense of control, and resilience).

RFS Committee: (L to R) Dan Weber, Allen Hirsch, Kristen McNiff, Shelley Fuld Nasso, Kirby Lewis, Allison Rosen, Candace Henley, Rebecca Esparza, Desiree Walker, Kelsey Nepote, Matt Goldman, Betsy Glosik, and Susan Strong





# Transforming Care



**HARMAR BRERETON, MD**

Dr. Brereton has dedicated his education, career, and life's work for nearly 40 years by researching and developing cancer services.

*"Perhaps one of the most impactful collaborations in Dr. Brereton's extraordinary career remains his early work and long friendship with Ellen Stovall. Through him, and in turn through the thousands of lives he has touched, Ellen's work continues, and her mission lives on."*

- KAREN M. SAUNDERS | PRESIDENT, NORTHEAST REGIONAL CANCER INSTITUTE



**DANA DORNSIFE**

Dana Dornsife began a nationwide public non-profit organization, Lazarex Cancer Foundation, dedicated to improving the outcome of cancer care in 2006.

*"Patient reimbursements and engagement are key, and Ms. Dornsife had the vision to understand that and the leadership to make it happen. Lazarex provides a key to hope...a key to life. I cherish every moment with my grandkids and my daughters, and I get that opportunity because of Dana Dornsife."*

- JACKIE HINKLEY | STAGE 4 METASTATIC BREAST CANCER PATIENT

## Recognizing innovation in improving cancer care for patients in America through the 2019 The Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care.

The Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care is a unique opportunity for patients and survivors to recognize pioneers who are transforming the cancer care system.

We recognized Harmar Brereton, MD and Dana Dornsife in 2019. To learn more about the 2019 Stovall Award winners, including short films about their career, please visit [canceradvocacy.org/Stovall-award](https://canceradvocacy.org/Stovall-award).

From left to right: Rep. Matt Cartwright, Dr. Harmar Brereton, NCCS CEO Shelley Fuld Nasso, Dana Dornsife, Rep. Mark DeSaulnier, Sen. Bob Casey. (Photo: Leslie E. Kossoff/LK Photos)



### EMPOWERING CARE THROUGH THE CANCER SURVIVORSHIP CHECKLIST

The Cancer Survivorship Checklist is a simple tool patients and caregivers can use as a guide for information critical to their care wherever they are on the cancer care continuum. Now, cancer survivors have a resource that can help them navigate the entire process, from active treatment into survivorship.

YOU CAN DOWNLOAD THE CHECKLIST NOW AT [WWW.CANCERADVOCACY.ORG](https://WWW.CANCERADVOCACY.ORG).

# Impacting Policy



The Spring Roundtable’s keynote speaker was the Food and Drug Administration’s outgoing Commissioner Scott Gottlieb, MD. We also welcomed National Cancer Institute director and acting Food and Drug Administration commissioner Ned Sharpless, MD. Other topics included the cost and experience of cancer in older adults, treatment and decision-making, and more.

At the Fall Roundtable, topics included access to care through clinical trials, improving cancer care for sexual and gender minorities, quality measurement, state and federal policy support to improve access and cost, and more.

[LEARN MORE ABOUT OUR POLICY ROUNDTABLES HERE.](#)

[NCCS co-hosted a Congressional briefing on Cancer Survivorship Issues](#) with the Oncology Nursing Society. Speakers described the needs of cancer survivors and their families, as well as NCI funded research on survivorship issues.

[NCCS joined an amicus curiae brief in the U.S. Court of Appeals](#) for the Fifth Circuit in the case Texas v. United States, citing the devastating impact patients would face should the court invalidate the Affordable Care Act and its protections for individuals with pre-existing conditions.

[The Cancer Care Planning and Communications Act \(CCPCA\), H.R. 3835, was reintroduced in the House of Representatives](#) by Rep. Mark DeSaulnier (D-CA) and Rep. Buddy Carter (R-GA), co-chairs of the Congressional Cancer Survivors Caucus. This legislation, aimed to increase access to comprehensive cancer care planning for Medicare beneficiaries, remains one of our top priorities. NCCS [hosted a webinar](#) to explain the details of CCPCA and how individuals can advocate for the legislation.

**NCCS hosted the 19th 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.**



# Promoting Advocacy

## NCCS HOSTED THE 6TH ANNUAL CANCER POLICY & ADVOCACY TEAM (CPAT) SYMPOSIUM AND HILL DAY

Advocates from across the country [came to Washington, D.C.](#) to gain a deeper understanding of policy issues, improve advocacy skills, and share personal experiences with Members of Congress to improve cancer care for everyone. Through panel discussions, interactive presentations, and breakout sessions, attendees learned about the history of the survivorship movement, state-based advocacy, financial toxicity, and the state of the cancer care system, and had workshops on telling their personal stories and meeting with policymakers.

[NCCS launched Elevating Survivorship](#), an exciting initiative that empowers and connects advocates with opportunities to improve survivorship care at the local level.

## ELEVATE AMBASSADORS HELPED PAVE THE WAY FOR COMMUNITY CANCER CARE

Through a competitive application process, NCCS chose ten Elevate Ambassadors to participate in the inaugural year of Elevating Survivorship. These cancer survivors and caregivers traveled from across the country to Washington, D.C. for the training program on survivorship care in the U.S.

### AMBASSADORS

Doris Cardwell, Spearfish, SD

Sarah Cohn, Philadelphia, PA

Erin Cummings, Boston, MA

Rachel Ferraris, Warner Robins, GA

Bradley Glassel, Lake Mills, WI

Loretta Herring, Adamsville, AL

Kimberly Richardson, Chicago, IL

Xenia Rybak, New York, NY

Hillary Stires, PhD, Arlington, VA

Virgie Townsend, Birmingham, AL

### EXAMPLES OF AMBASSADOR PROJECTS INCLUDE:

- A relationship-building program, called CTAP (Cancer Trainee and Advocate Program), between research trainees and patient advocates designed to improve cancer research.
- Creation of a Public Service Announcement about long-term side-effects for survivors of Hodgkin Lymphoma.
- A conference to educate survivors about what they should expect from their health care team in a very rural area where survivorship resources are difficult to find.
- A roundtable discussion in the state of Illinois with oncologists, researchers, and patients discuss disparities in rare women's cancers.
- Development of a patient advocacy group who educate the local community on survivorship issues, focusing on African American survivors.



◀ 2019 Elevate Ambassadors

# Promoting Advocacy

## SURVIVORSHIP SURVEY

NCCS launched a [survivorship survey](#) to identify gaps in care during and after cancer treatment. Nearly 1,400 survivors completed the questionnaire, which led to some important findings. The Association for Community Cancer Centers (ACCC) launched a companion survey of its members.

## TREATMENT EXPERIENCES

- Patients report many physical and emotional side effects, with fatigue and anxiety at the top of the list.
- Patients report that while health care providers (HCPs) are helpful at addressing their physical side effects, they are far less helpful at addressing fatigue, anxiety, depression, and cognitive effects.

*“I do wish that my health care team did more to address the emotional side effects, particularly in screening for it. I developed a lot of anxiety, but I just thought it was normal. Only in retrospect did I realize I had a problem.”*

- SURVEY RESPONDENT



## POST-TREATMENT INFORMATION AND CARE

- Few feel very prepared for the transition to post-treatment, nor informed about how to manage their health post-treatment.
- While most patients have spoken to a health care provider about post-treatment care, over half say they asked their doctor/HCP, and far fewer say their provider initiated these conversations.
- Satisfaction with post-treatment care is varied, with few describing it as excellent. As a result, more rely on online sources for information rather than their HCPs.

*“I wish that my health care team would address survivorship issues and long-term effects of my cancer diagnosis. At this point I am just told to call if there are any changes in the way that I feel, this leaves me feeling uneasy and uncertain about the future of my health.”*

- SURVEY RESPONDENT

## SURVIVORSHIP NEEDS

When asked to identify their level of concern about a range of issues, financial issues tops the list (getting/keeping health insurance, having financial support), followed by managing ongoing side effects, uncertainty about the future, and having the energy to make it through the day.

- There is clearly a disconnect between patient concerns and support from health providers. Less than a third rate their HCP as “very helpful” on their top issues.
- Many are interested in survivorship resources, especially programs for managing long-term symptoms, but few say these are available from the HCPs today.



# NCCCS in the News



▲ **NCCS CO-FOUNDER AND CPAT MEMBER ON USA TODAY**

USA Today featured NCCS co-founder and CPAT member, Susan Leigh. She shared her experience being diagnosed with cancer for the first time at age 24. Susan discussed how cancer has impacted her life, the founding of NCCS, and the importance of advancing the understanding of survivorship issues.



◀ **THE WALL STREET JOURNAL FEATURES ELEVATING SURVIVORSHIP**

Wall Street Journal contributor Laura Landro featured the Elevating Survivorship Initiative in her article titled, "You've Survived Cancer. What Comes Next?"



◀ **NCCS BOARD MEMBER ON THE NATIONAL PUBLIC RADIO**

NCCS board member, Julia Rowland, PhD, joined Ms. Landro on the National Public Radio's program, On Point, to discuss the article and the challenges of cancer survivorship, including the Elevating Survivorship Initiative.

▶ **NCCS CEO QUOTED ON THE WASHINGTON POST**

NCCS CEO, Shelley Fuld Nasso, was quoted in Steven Petrow's article in The Washington Post about his 35-year "cancerversary."



# Financials

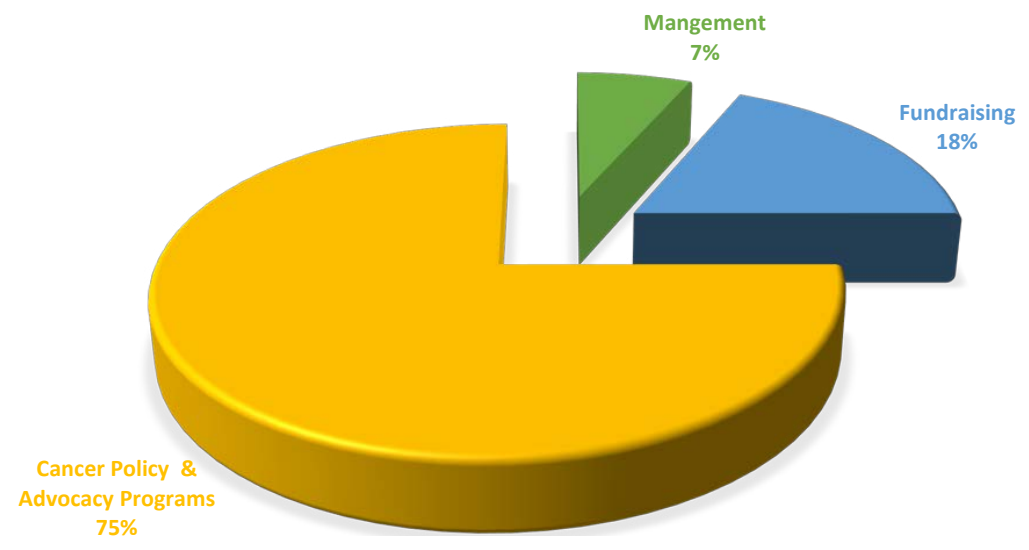


Statement of activities and changes in net assets for the year as of December 31, 2019.

	2019
<b>REVENUE</b>	
TOTAL REVENUE	\$1,981,536
<b>EXPENSES</b>	
TOTAL EXPENSES	\$1,698,922
<b>CHANGE IN NET ASSETS</b>	<b>\$405,995</b>
<b>NET ASSETS (BEGINNING OF YEAR)</b>	<b>\$716,099</b>
<b>NET ASSETS (END OF YEAR)</b>	<b>\$1,122,094</b>

The 2019 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, 2019.

	2019
<b>CURRENT ASSETS</b>	
TOTAL CURRENT ASSETS	\$627,630
<b>OTHER ASSETS</b>	
TOTAL OTHER ASSETS	\$771,586
<b>TOTAL ASSETS</b>	<b>\$1,399,216</b>
<b>CURRENT LIABILITIES</b>	
TOTAL CURRENT LIABILITIES	\$277,123
<b>NET ASSETS</b>	
TOTAL NET ASSETS	\$1,122,094
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$1,399,216</b>

# Thank You to Our Supporters

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Inovalon, Inc.  
Pittsburgh Penguins LP

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