



National Coalition for Cancer Survivorship

ANNUAL REPORT 2018



“

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

”



Dear Friends,

2018 was a tremendous year for the National Coalition for Cancer Survivorship (NCCS) as we continue to empower survivors and impact cancer policy. As you will see in this report, we saw wonderful progress in both, as existing programs and outreach continue to grow, and we launched three new initiatives aimed to improve survivorship and how patients experience cancer.

Throughout the year, we were outspoken leaders to protect the Affordable Care Act (ACA) and its critical patient protections and access to quality and affordable care. While thankfully Congress was stopped from repealing the ACA in 2017, threats to the law shifted in 2018 to individual states, regulatory action, and the judicial system. NCCS was active in advocating on each of these fronts, highlighting how critically important the ACA is to patients and their families both medically and financially.

There continues to be an incredible physical, emotional, and financial cost of cancer on millions of Americans, making our advocacy as important as ever. Thank you for supporting NCCS as we transform the health care system for all touched by cancer.

Sincerely,

A handwritten signature in white ink that reads "Shelley". The signature is fluid and cursive, with a long, sweeping tail that extends to the right.

Shelley Fuld Nasso, MPP
Chief Executive Officer

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-coordinating their care between numerous providers shouldn't be on the list. Each patient should have a care quarterback that tracks, organizes, and initiates interactions when appropriate.



Access to affordable, quality health care

Before the passage of the Affordable Care Act (ACA) in 2010, cancer patients faced many barriers to quality health care, including insurance denials because of pre-existing conditions and out-of-pocket expenses that could land them in debt. 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 patient's goals and values

Standard of care must go beyond just diagnosis and treatment of the cancer. Instead, it must include substantive doctor-patient communication to incorporate patients' goals and values in all decisions throughout the cancer care continuum.



Payment reforms to drive patient-centered, value-based care

The country is moving away from the current fee-for-service system, which incentivizes treatments based on the quantity of care rather than quality of care. Instead, we need to adopt shared-decision making, evidence-based care, and patient-reported outcome measures as foundations for value-based care.



High-quality review to ensure safe and effective cancer drugs reach patients

We must ensure 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.

A portrait of a young man with short, wavy brown hair and a light beard, smiling. He is wearing a white dress shirt and a purple and blue striped tie. The background is a soft, out-of-focus grey.

Skyler Taylor

“I am motivated by the satisfaction that I am impacting the cancer community before I am able to actually practice medicine.”

ADVOCATE SPOTLIGHT

I first learned about NCCS at CancerCon 2018 in Denver, CO. After listening to NCCS Communications Director Dan Weber's session on the importance of advocacy, I wanted to join and become a survivor advocate.

The next summer, I went to NCCS' Cancer Policy and Advocacy Team (CPAT) symposium in Washington D.C. It was there that I received advocacy training before speaking with my Representative and Senators on Capitol Hill about survivorship legislation. Since that experience, I've taken the skills learned at CPAT to my local government in Springfield, Illinois. I later had the opportunity to interview Dan for the survivor blog and podcast I founded, Catalyze Living.

Currently, I am a second-year medical student at Southern Illinois University School of Medicine in Springfield, Illinois. I married the love of my life in December, and we are excited to begin our life together. While I am keeping an open mind about my future field of practice, it would be unfair to deny that I have a vested interest in oncology and especially the young adult cancer survivor community. I am actively engaged in cancer epidemiology research, and presented research findings on several occasions. I am also currently the Vice-Chair of my local American Cancer Society's board. These commitments keep me busy, but I am motivated by the satisfaction that I am impacting the cancer community before I am able to actually practice medicine.



Rep. Rodney Davis (IL-13) and Skyler meet in the Congressman's office during the NCCS Capitol Hill Day.



Year in Review.

**In 2018, NCCS saw changes to both
our Board of Directors and staff.**



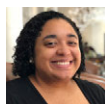
Philip Dufour
Board Member

Philip joined the NCCS Board of Directors in the spring of 2018. Philip has a long history with NCCS and was a close friend of Ellen Stovall. He owns and operates the Dufour Collaborative in Washington, D.C., which produces some of the biggest events in the city. Previously, he co-founded the J Street Group, LLC, worked with the Elizabeth Glaser Pediatric AIDS Foundation, and served as the Social Secretary for Vice President Al Gore and as Mrs. Tipper Gore's Deputy Chief of Staff.



Taylor Ferrell
Board Member

Taylor Ferrell joined the NCCS Board in the fall of 2018. He is an environmental attorney with the Department of Justice. He formerly worked in the Pentagon and in the White House under President Obama. A cancer survivor, he lives in Washington D.C., with his wife and daughter.



Brittani Harris
Development and Events Coordinator

Brittani Harris joined NCCS as Development and Events Coordinator in 2018. She dedicates herself to supporting all fundraising activities, including donor and public relations, direct mail appeals, and special events. She manages the logistics for several of NCCS' events: the Cancer Policy Roundtables, the Cancer Policy and Advocacy Team (CPAT), and the Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care. Brittani uses her warm and empathic approach to commit herself to helping NCCS engage and educate cancer survivors nationwide.

When she is not working, Brittani likes to spend time with her family and friends, visit museums, and enjoy new restaurants in the Metro D.C. area.

New Projects Added

NCCS launched a new project to measure quality of life for cancer survivors. NCCS is developing a patient-centered quality measure to assess survivors' ability to establish a new 'normal' when it comes to daily function during and after cancer treatment. This important effort is being funded by the American Institutes for Research with support from the Robert Wood Johnson Foundation.

NCCS kicked off Elevating Survivorship, an exciting new initiative to provide advocates with opportunities to improve survivorship care at the local level. As part of this initiative, we launched a survivorship survey to identify gaps in care, and we are excited that over 1,300 survivors completed the questionnaire. Survey results will be made available in 2019.

Survivorship Checklist: NCCS was awarded a grant to develop a one-page checklist (front and back), which patients can get from their provider or download online, and which outlines critical steps survivors can take to play an active role in managing their care. While the checklist will help with the transition to post-treatment care, the content will also be applicable throughout the cancer journey. The checklist will be completed in 2019.

CPAT Members engage in a discussion during the Symposium.



Transforming Care.

Rep. Jamie Raskin (MD-8), Rep. Debbie Wasserman Schultz (FL-23), Dr. Norman Coleman, Gay Crawford, Rep. Anna Eshoo (CA-18), and Shelley Fuld Nasso at the Stovall Award Reception.



STOVALL AWARD

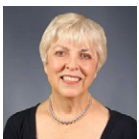
The Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care was again a resounding success. From another exceptionally qualified field of candidates, the Selection Committee chose Gay Crawford and C. Norman Coleman, MD, as this year's honorees.

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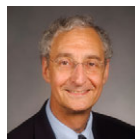
PRICE TRANSPARENCY EDITORIAL

NCCS CEO Shelley Fuld Nasso joined co-authors Dr. Tina Shih and Dr. Yousuf Zafar on an editorial in the journal *PharmacoEconomics* entitled, “Price Transparency for Whom? In Search of Out-of-Pocket Cost Estimates to Facilitate Cost Communication in Cancer Care.”



Ms. Gay Crawford

Founding Director of Cancer CAREpoint, is a two-time cancer survivor and has been a tireless advocate for cancer patients and families for more than four decades.



Dr. Norman Coleman

A radiation oncologist, is a leading provider advocate for patient-centeredness; emphasizing access to care, respect for patient preferences, and coordination and integration of care.

CANCER POLICY ROUNDTABLES

NCCS hosted the 18th year of semi-annual Cancer Policy Roundtable “think tank” meetings, bringing together providers, researchers, advocates and policy makers to discuss the latest in cancer policy.

The Spring roundtable looked at what’s next for access to affordable health care, cancer care planning, overdiagnosis and overtreatment, disparities in care, and how proposals to reform Medicare will affect cancer patients and quality of care.

At the Fall Roundtable, held in November right after the midterm elections, topics included how the election results might impact health care, drug pricing, transitions in survivorship care, alcohol and cancer, and the FDA’s Oncology Center of Excellence.



◀ INTRODUCED CCPC ACT

NCCS worked with Congressmen Mark DeSaulnier (CA-11) and Ted Poe (TX-2) to introduce the Cancer Care Planning and Communications (CCPC) Act, H.R. 5160, which would establish a Medicare reimbursement code for cancer care planning.

▶
Rodney Whitlock, Zach Marshall, and Lindsay Houff discuss the midterm election’s impact on cancer research and care at the Fall 2018 CPR.



Impacting Policy.



- ▲ A panel with (left to right) Peter Ubel, MD, Duke University; Blase Polite, MD, MPP, FASCO, The University of Chicago; Kelsey Lang, MPP, Bristol-Myers Squibb; Tanisha Carino, PhD, FasterCures; and Douglas Blayney, MD, Stanford University Medical Center (moderator); discuss drug pricing and its impact on cancer care.

CPAT members Jamie Ledezma (pictured right) and Randy Broad shared their personal stories as cancer survivors during Minority Leader Nancy Pelosi's press conference on why guarding pre-existing condition protections is so critical.





CPAT SYMPOSIUM AND HILL DAY

NCCS hosted the 5th 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 their advocacy skills, and share their personal experiences with Members of Congress in an effort to improve cancer care for everyone. Through panel discussions, interactive presentations, and breakout sessions, attendees learned about the history of the survivorship movement, telling your personal story, state-based advocacy, financial toxicity, the state of the cancer care system, and meeting with policymakers.

CPAT SYMPOSIUM AGENDA TOPICS:

- “THE SURVIVORSHIP MOVEMENT: YESTERDAY, TODAY, TOMORROW”
- “STATE-BASED ADVOCACY: STATE CANCER PLANS AND COALITIONS”
- WORKSHOP: “COMMUNICATION AND THE LANGUAGE OF CANCER”
- “FINANCIAL TOXICITY” WITH DR. YOUSUF ZAFAR
- “THE STATE OF THE CANCER CARE SYSTEM 2018”
- “STAGING YOUR IMPACT: MEETINGS WITH POLICYMAKERS”

Medical students taking part in the CUPID (Cancer in the Under-Privileged Indigent or Disadvantaged) program who attended the Symposium.



Medical student Alexandar Tejeda (Left), CPAT Member Tiah Tomlin, and Rep. John Lewis (GA-5) meet in his office on Capitol Hill.

STATE-BASED ADVOCACY WEBINAR

NCCS hosted a webinar for our CPAT members to learn more about state-based advocacy, providing an overview of state cancer plans and opportunities to engage.

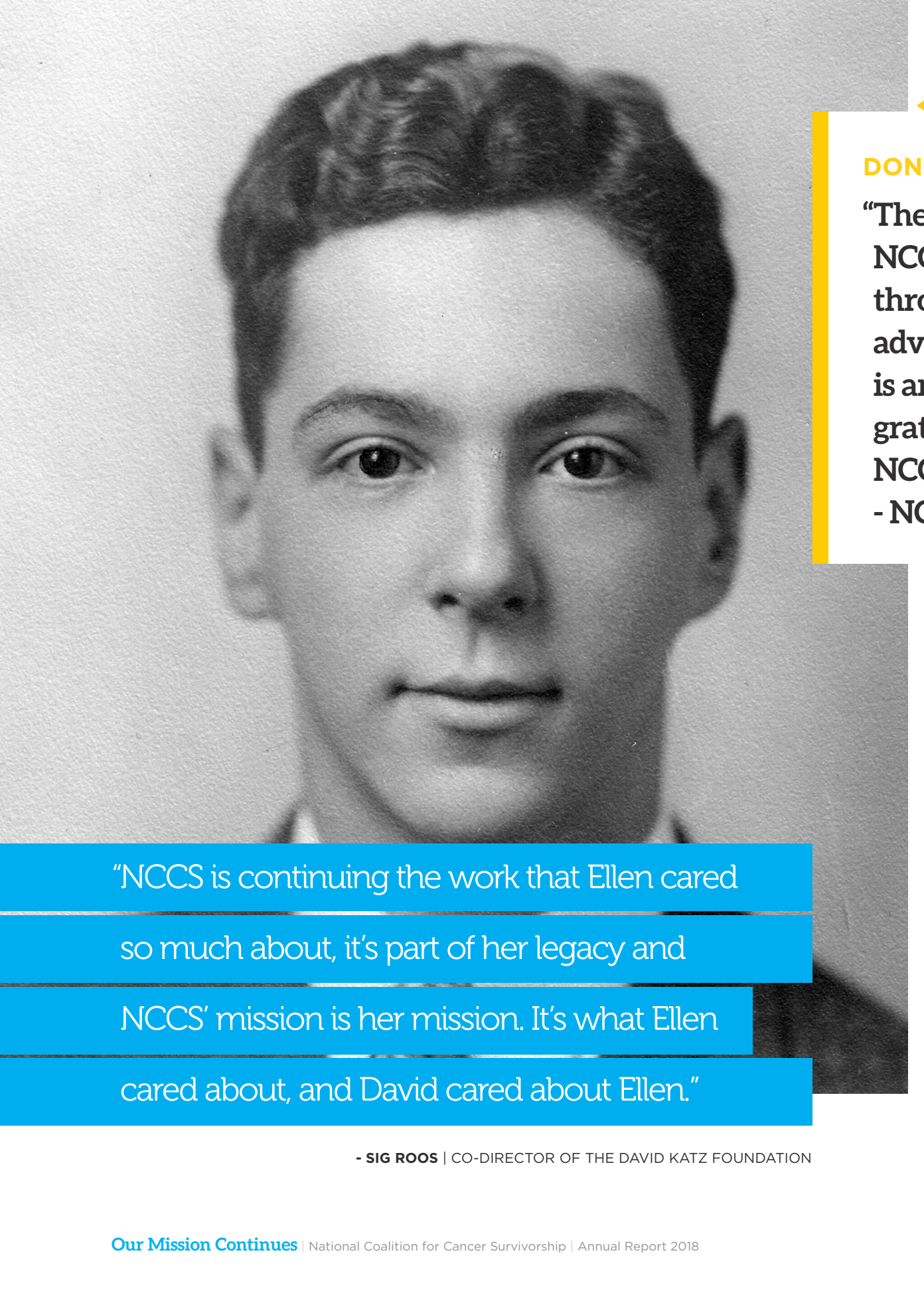
FEAR OF CANCER RECURRENCE WEBINAR

Our most popular webinar of the year was entitled "Understanding Fear of Cancer Recurrence." Dr. Sarah Reed, UC Davis, presented her research and shared practical information to help survivors, caregivers, and others ease the anxiety associated with cancer recurrence. A recording of the webinar is available on the NCCS website.

Promoting Advocacy.

Medical student Alyse Ragauskas (left) and CPAT Member Rachel Ferraris meet with Congressman Sanford Bishop (GA-2) in his Capitol Hill office.





DON

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"NCCS is continuing the work that Ellen cared
so much about, it's part of her legacy and
NCCS' mission is her mission. It's what Ellen
cared about, and David cared about Ellen."

- SIG ROOS | CO-DIRECTOR OF THE DAVID KATZ FOUNDATION

DONOR SPOTLIGHT

The legacy of David Katz and his generosity lives on at NCCS. Ellen's loving and dynamic family supported her through multiple cancer diagnoses and her decades of advocacy work, and the David Katz Foundation's support is another lasting example of their kindness. We are grateful that the foundation board continues to view NCCS as a worthy recipient of Mr. Katz's generosity." NCCS CEO, Shelley Fuld Nasso.

The David Katz Foundation is a consistent supporter of NCCS, donating nearly \$100,000 over the past 20 years, to advance our work on behalf of cancer survivors and their families.

David Katz was born in 1920, in Honesdale, Pennsylvania, and was the older cousin of Ellen Stovall, CEO of NCCS from 1992 through 2008. David was an executive in his family business, the Katz Underwear Company in Honesdale. As the first child of her generation in the family, Ellen was David's "favorite," as her family describes. Ellen and David were very close and especially enjoyed spending time together every Sunday morning when the families would get together.

Years later, when Ellen was diagnosed with cancer, David supported her through her journey, and his support continued when Ellen embarked on her career in cancer advocacy.

Before David passed away, he established a foundation that would continue to invest in important causes that were close to his heart, including Ellen's work in cancer survivorship.

NCCS is grateful to the David Katz Foundation, and his family members who continue his legacy, for the many years of dedication to our mission on behalf of cancer patients like Ellen, and millions more.

Sig Roos with Ellen Stovall.



Financials.

Statement of activities and changes in net assets for the year ended December 31, 2018.

	2018
REVENUE	
TOTAL REVENUE	\$1,673,449
EXPENSES	
TOTAL EXPENSES	\$1,963,267
CHANGE IN NET ASSETS	\$289,818
NET ASSETS (BEGINNING OF YEAR)	\$1,006,442
NET ASSETS (END OF YEAR)	\$716,624

The 2018 numbers represented above are preliminary and are subject to change upon audit.

NCCS Board member Taylor Ferrell and his mother, Susan Weems, attend the 2019 Ellen Stovall Award Reception in Washington, D.C.



National Coalition for Cancer Survivorship statement of financial position December 31, 2018.



2018

CURRENT ASSETS

TOTAL CURRENT ASSETS	\$396,465
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OTHER ASSETS

TOTAL OTHER ASSETS	\$634,879
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TOTAL ASSETS	\$1,031,344
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CURRENT LIABILITIES

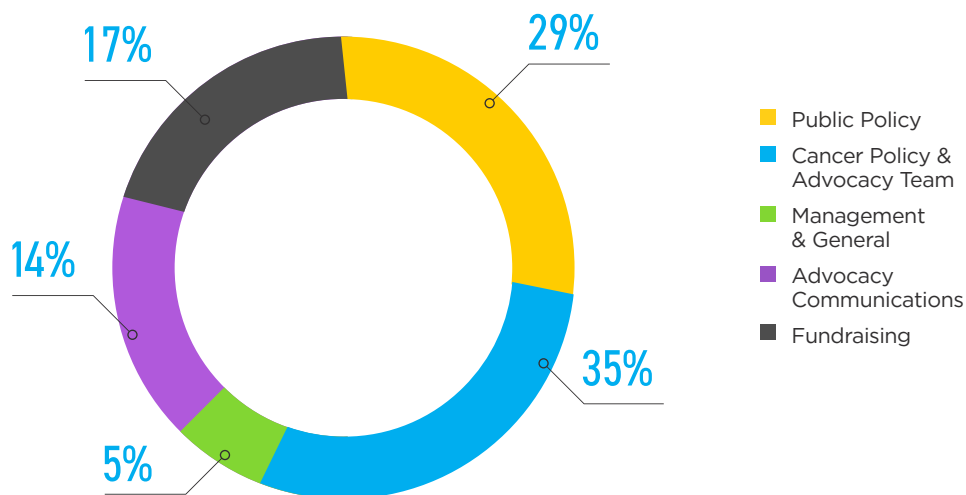
TOTAL CURRENT LIABILITIES	\$314,720
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NET ASSETS

TOTAL NET ASSETS	\$716,624
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TOTAL LIABILITIES AND NET ASSETS	\$1,031,344
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EXPENSES AT A GLANCE



Donors.

\$100,000+

Amgen
Bristol-Myers Squibb Company
Genentech, Inc.
Novartis Pharmaceuticals Corporation

\$50,000-\$99,999

AbbVie Inc.
American Institutes for Research
Celgene Corporation
Johnson & Johnson Healthcare Systems Inc.
Kite Pharma, Inc.
Merck & Co.
Pfizer Oncology

\$25,000-\$49,999

Astellas Pharma US
Boehringer Ingelheim Pharmaceuticals Inc.
Eisai, Inc.
Jazz Pharmaceuticals, Inc.
Lilly USA, LLC
Pharmaceutical Research & Manufacturers of America
Pharmacyclics LLC
Takeda Oncology

\$10,000-\$24,999

American Society of Clinical Oncology
Biotechnology Industry Organization
Gilead Sciences, Inc.
Laurie Isenberg and Joel Roos
Kings Care Foundation
Tesaro Inc
Turner & Goss LLP
Sandy G. Welton

\$5,000-\$9,999

Michael and Kim Kappel
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Verastem, Inc.
Eleanor Winter and Dan Backo

\$1,000-\$4,999

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Association of Community Cancer Centers
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Briana Black and Jonathan Stovall
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UP TO \$999

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Roberta Albany
Dawn Aldrich
Yolanda Alleyne
AmazonSmile Foundation
Melinda Bachini
Joyce Bader
Joey Barash

Barbara Barea
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Cynthia Brenner
Randall Broad
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Theresa Davis
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Ardie Delforge Larkins
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Claire Farnum
Rachel Ferraris
Taylor Ferrell
Sandra Finestone
Susan Fisher
Benjamin Fishman
Heidi Floyd
Diane Frangos
Valerie Fraser
Liza Fues



◀ NCCS Board Member Julia Rowland, PhD, and NCCS Co-founder Fitzhugh Mullan, MD, at the Stovall Award Reception.

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San Antonio

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Brookings Institution

John V. Cox, DO

Parkland Hospital

Bob Erwin

Marti Nelson Cancer Foundation

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Vice President and Chief Innovation Officer
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Michael Link, MD

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UnitedHealthcare

Mary McCabe, RN, MN

Director, Cancer Survivorship Initiative
Memorial Sloan-Kettering Cancer Center
(retired)

Therese M. Mulvey, MD, FASCO

Massachusetts General Hospital

Lee Newcomer, MD

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Thomas Smith, MD

Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins University

Jennifer S. Temel, MD

Massachusetts General Hospital



Dr. Yousuf Zafar presents data on financial toxicity at the 2018 CPAT Symposium.

Board Members.



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Beckwith



Philip
Dufour



Taylor
Ferrell



Ben
Fishman



Laurie
Isenberg



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Kappel



Jennifer
McGihon



Julia
Rowland, PhD



Lyman (Sandy)
Welton



Eleanor
Winter

Gay Crawford, a 2018 Stovall Award honoree, is presented with the award by her Congresswoman, Rep. Anna Eshoo (CA-18).

NCCS Staff

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Eric Gordon

Brittani Harris

Lindsay Houff

Elena Jeannotte

Shelley Fuld Nasso

Kelsey Nepote

Woulita Seyoum

Etsegenet Tekeste

Dan Weber

Cancer Survivor





▲ CPAT Member Florence Kurttila with Congressman Ami Bera (CA-7) during the NCCS Capitol Hill Day.



▲ Rep. Anna Eshoo (CA-18) shares remarks during the 2018 Stovall Award Reception.



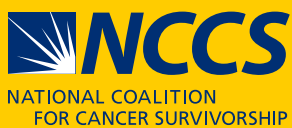
▲ Medical student and CUPID participant, Ryan Erdwins, with Congresswoman Jaime Herrera Beutler (WA-3).

“

**With communication
comes understanding
and clarity;
With understanding,
fear diminishes;
In the absence of fear,
hope emerges;
And in the presence
of hope, anything
is possible.”**

Ellen L. Stovall

Blog post for National Cancer Survivors Day in 2015



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Suite 930
Silver Spring, MD 20910
Canceradvocacy.org