

National Coalition for Cancer Survivorship

ANNUAL REPORT 2018









44 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

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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 preexisting 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.

Skyler avlor

"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-Center 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.



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STOVALL AWARD

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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.

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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.

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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

Our Mission Continues | National Coalition for Cancer Survivorship | Annual Report 2018



DNOR SPOTLIGHT

he legacy of David Katz and his generosity lives on at ICCS. Ellen's loving and dynamic family supported her nrough multiple cancer diagnoses and her decades of dvocacy work, and the David Katz Foundation's support another lasting example of their kindness. We are rateful that the foundation board continues to view ICCS 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.



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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.

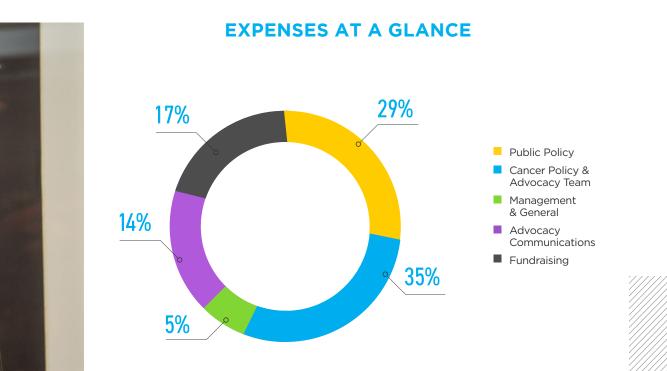
NCCS Board member Taylor Ferrell and his mother, Susan Weems, attend the 2019 Ellen Stovall Award Reception in Washington, D.C.



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

	2018
CURRENT ASSETS	
TOTAL CURRENT ASSETS	\$396,465
OTHER ASSETS	
TOTAL OTHER ASSETS	\$634,879
TOTAL ASSETS	\$1,031,344

CURRENT LIABILITIES	
TOTAL CURRENT LIABILITIES	\$314,720
NET ASSETS	
TOTAL NET ASSETS	\$716,624
TOTAL LIABILITIES AND NET ASSETS	\$1,031,344



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 Musa and Tom Mayer Connie and John Rakoske Verastem, Inc. Eleanor Winter and Dan Backo

\$1,000-\$4,999

American Society for Radiation Oncology Association of Community Cancer Centers Andrea Becker Samira Beckwith Marjorie C. Berg Briana Black and Jonathan Stovall lane and leff Bulman **Capitol Document Solutions** C. Norman Coleman, MD John V. Cox, DO Kate Ditzler Darian Downs Lucinda N. Dudley Kevin Fuld Shelley Fuld Nasso and Michael Nasso Patricia Ganz MD Elizabeth Goss, JD International Cancer Expert Corps Ellen Jantzen David Katz Foundation Inc Willam Katz Fitzhugh Mullan, MD Omaze, Inc. The Original Pancake House Julia Rowland PhD Leslie Seeman Thomas Smith. MD Taiho Oncology David van Hoogstraten and Michelle Kayon

UP TO \$999

AEG Cycling LLC Sangeeta Agarawal Roberta Albany Dawn Aldrich Yolanda Alleyne AmazonSmile Foundation Melinda Bachini Joyce Bader Joey Barash Barbara Barea Sanchia Batt David Bernstein Liza Bernstein June Blair Antony Blinken Donna Boss Susie A. Brain Susan Bram Cynthia Brenner Randall Broad Ruth Brodsky David Butler Stuart Butler Darcy Lynn Campbell John Cantril Robert G. Carter Alice Cave Elizabeth Clark Mark Corroto Caroline Corum Dale Cowan Sarah Cowen Gay Crawford Donald Davenport Theresa Davis Carla De Landri Ardie Delforge Larkins Davida T. Deutsch Jean Di Carlo-Wagner Hildy Dillon Sarah Divers Walter Divers Janet Dodd Tom Dowling Suzanne B. Ducat Jennifer Elliott Rebecca Esparza Fred Fanchaly Sarah Farnam Sofia Farnam 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. lane Fuld Stephen Fuld Cynthia Gagen Mary Garlick Roll **Richard Gelb** Zara Gerber Miriam Goldberg Valerie Goldstein Harriet L. Granger Elaine K. Greenberg Larrie and Joyce Greenberg Jane D. Greene Beverly Greenfeig Kenneth Handel Wendy Harpham Cathy Harvey Belinda D. Hecht Diane Heditsian Stephen E. Hentges Michael Herman Loretta Herring Patsy Hinson Barbara Hoffman Thelma Hoffman **Richard Hoffstein** Nina B. Homel Lindsay Housden Jian Huang Daphne Huber Susan Huerta IBM Employee Charitable Campaign Elena Jeannotte Sheyla Jensen-Boyes Hartley Jones Lee Jones Page Kennedy Michelle Kennedy-Gonzales Barbara (Cookie) Kerxton Ralph and Lisa Kleinman James Knudson Linda Krebs Susan Krivacic Regina Kurrasch Florence Kurttila Tanya A. Lampert Jamie Ledezma Susan Leigh Sarah Leinart Delilah Lewis Stephen J. Lewis and Alison Wylegala

Alexandra Lucy Liza P. Lucy Carole Mattis Deborah Mayer Joyce McCann Lora McCann Michael McCautey Jennifer McGihon Robert (Bob) M. Mclean Yvonne McLean Florence Tucker Melancon Shirley A. Mertz Neil Mitchell Steven Moddelmog Joanne Moffat Gael Mooney Kathy Oliver **Oncology Nursing Society** Cindy O'Neal Veronika Panagiotou Jeffrey Passel Frances Penan Marylu Penan & Scott, P.C. Judy Plymale Wilbur M. Rankin Tran Ream Sylvia Reaves Rhonda Rechkemmer Katherine Resch Peter Rez **Corinne Roberts** Sigmund Roos and Ruth Rohde Diane Rose David Roth Seana Roubinek Laurie Rozgonyi Xenia Rybak Susan L. Scherr Sarah Scholle Lisa Schulmeister Steven Schurkman Jerome Seidenfeld Debora Setuain Woulita Seyoum Steven Shak Tara Shetler Tobyanne Sidman Jane H. Singer Maxine Solvav Ellen Sonet Alicia Staley

Marc G. Stanley Michelle Strollo Susan Strong **Cornelius Sullivan** Andrew Tao Nicole Tapay Skyler Taylor Stuart R. Taylor **Gladys** Thomas Stacey Tinianov Tiah Tomlin Brian Trinkle Eric Trules Anne Turnage Joann K. Vesole Cicily Waeger Desiree Walker Scott Waller Diana and Jim Webb Susan Weems Susan Weiner Mike Weiss Robert and Pearl Weiss Brian P. Wells James Wilson Ronnie Wilson **Robert Winick** Lisa A. Wise Adele L. Wolf Dr. Robert Young Gary Zahrbock Lynnee Zaklin Bradley Zebrack Barbara Zimmerman Lorraine Zocchi John Zuzek

Policy Advisors.

Gregory J. Aune, MD, PhD University of Texas Health Science Center, San Antonio

Stuart M. Butler, PhD Brookings Institution

John V. Cox, DO Parkland Hospital

Bob Erwin Marti Nelson Cancer Foundation

Pamela Haylock, PhD, RN, FAAN Sul Ross State University

Michael Kolodziej, MD Vice President and Chief Innovation Officer ADVI Health, Inc.

Michael Link, MD Stanford Cancer Institute

Jennifer Malin, MD 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 UnitedHealthcare (retired)

Kevin C. Oeffinger, MD Duke Cancer Institute

Ann H. Partridge, MD, MPH Dana-Farber Cancer Institute

Kavita Patel, MD Brookings Institution

Derek Raghavan, MD, PhD, FACP, FRACP Levine Cancer Institute

Jeffrey Scott, MD Strategic Oncology Consultants

Joshua M. Sharfstein, MD Johns Hopkins Bloomberg School of Public Health

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.



Chair Samira Beckwith



Ben Fishman



Jennifer McGihon













Michael Kappel



Lyman (Sandy) Welton

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





Zach Biondo Eric Gordon Brittani Harris Lindsay Houff Elena Jeannotte Shelley Fuld Nasso Kelsey Nepote Woulita Seyoum Etsegenet Tekeste

🕺 Dan Weber







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

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



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."





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