



30

Our Mission Continues...
2016 Annual Report



▼ Shelley Fuld Nasso

2016
of the
Surviv

We advocate for quality cancer care
for all individuals touched by cancer.



marked the **30th anniversary** of the National Coalition for Cancer Survivorship (NCCS).

From the first organizing meeting in Albuquerque, New Mexico, to the halls of Congress in Washington, D.C., NCCS quickly established itself as a national leader in cancer policy advocacy. We are the oldest survivor-led advocacy organization in the nation, and I am proud and humbled to serve as CEO for an organization with such a critical mission and an influential history. NCCS first established survivorship issues, and continues to be an outspoken leader to improve care for patients and families from the moment of diagnosis.

No one was a more dedicated or effective advocate on these issues than former NCCS CEO Ellen L. Stovall, who sadly and suddenly passed away in January 2016. Her dedication to advocacy and her personal experience with cancer were a source of inspiration at NCCS. Her death further fueled our dedication to transforming cancer care in her memory and improving the experience for millions of survivors and their families. The outpouring of support at her memorial service, where hundreds of people attended to pay their respects and honor her life as a pioneer, was heartening to her family, friends, and colleagues. She continues to be missed and will be always remembered.

Thank you for your continued support of NCCS. I am excited for what 2017 and the next 30 years holds for NCCS as we transform cancer care to be more inclusive of the needs and values of everyone impacted by cancer.

Sincerely,



Shelley Fuld Nasso
Chief Executive Officer

NCCS policy priorities



**Care coordination
and planning**



**Care that incorporates
patients' goals and values**



**Affordable, accessible,
quality health care**



Payment reform



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



Jen.

“I never thought I’d get to call myself a ‘survivor.’ I believe that term comes with a certain responsibility to give back to the cancer community. Because of what I’ve been through, I feel passionate about the work NCCS is doing to ensure better survivorship for all cancer patients.”

This is Jen, who attended the NCCS Cancer Policy Roundtable last fall. She is a wife, a mother, and a lawyer, and one of the **16 million reasons** why NCCS is working to transform cancer care.

01

Number of times Jen was misdiagnosed with Metastatic Breast Cancer.

02

Years of no evidence of disease.

05

Years of treatment she endured.

05

Months old her son was when she was misdiagnosed.

07

Number of doctors/specialists on her care team she had to coordinate.

80

Number of combined treatments she underwent.

\$1M^{+/-}

Cost of her care to date.

- ◀ Jen's story highlights several areas where NCCS is focused on improving cancer care policy by engaging on Capitol Hill, in federal agencies, and with advocates across the country.

Year in Review.

2016 was filled with accomplishments and growth for NCCS. Our capacity to create change in our health care system was made even stronger as we added several individuals to our team:



Lindsay Houff
Public Policy Manager



Kelsey Nepote
Advocacy Manager



Brandi Stevenson
Office Manager and
Development Associate



Dan Weber
Director of Communications



877.NCCS.YES
Cancer Sucks
www.canceradvocacy.org

877.NCCS.YES
Choose Hope
www.canceradvocacy.org



Transforming Care.

▼ Photo by: Andrew Tao





01

Launched the Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care

NCCS presented the inaugural Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care to Douglas W. Blayney, MD, FACP. Dr. Blayney is past president of the American Society of Clinical Oncology (ASCO) and worked closely with Ellen for many years to improve the quality of cancer care for survivors. Moving forward, this award will be an annual, nationwide competition to identify a provider or practice that is providing cancer patients and their families with exceptional, coordinated patient-centered care. Dr. Blayney will serve as co-chair of an advisory committee to establish the award's criteria and evaluate nominations. *For more info, visit StovallAward.org*

02

Oncologist-Patient Focus Groups

NCCS held focus groups with oncologists and patients that further illustrated the significant divide in doctor-patient communication and some of the challenges that persist. With both groups, it was clear that attitudes and mindsets differed greatly, further complicating how to tailor strategies to improve communication. Especially with the patients, who ranged from a “doctor knows best” attitude to a “patient takes charge” approach, it was clear a one-size-fits-all approach would not be sufficient. The findings show that work remains to customize approaches to increase effective doctor-patient communication, and highlights areas for further investigation. We published a paper on this research in the October issue of *Evidence-Based Oncology*.

03

Raising Awareness for Survivorship

NCCS also represented cancer survivors on the American Society of Clinical Oncology's Cancer Survivorship Committee, and co-authored a paper in the *Lancet Oncology* entitled, “Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA.”

Jonathan Stovall and Shelley Fuld Nasso present Dr. Blayney (center) with the Stovall Award.



01

Cancer Policy Roundtables

NCCS hosted its 16th year of semi-annual Cancer Policy Roundtable (CPR) “think tank” meetings, convening stakeholders to discuss health care policy improvements. The spring CPR, titled “What Do Cancer Patients Value in Treatment Options, Communications, and Care?”, included a panel of cancer survivors discussing what it means to be an empowered patient and how they navigated the cancer care system to obtain the care that matches their goals and values. We also discussed improving doctor-patient communication and including patient values in cancer drug research and development.

The fall CPR, “Post-Election: What’s Next for Cancer Policy?”, focused on what the results of the 2016 election mean for cancer survivors and health care policy moving forward.

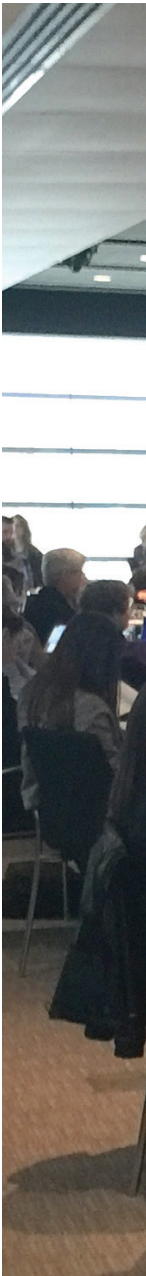
President Obama signs 21st Century Cures Act into law, with \$1.8 billion in funding for the Cancer Moonshot.



02

Quality Measurement

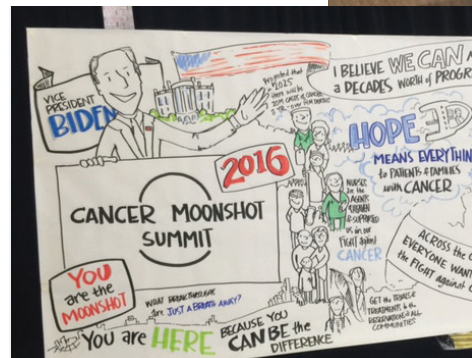
Quality measurement is an important component of reforms to the health care system to deliver patient-centered care that is based on value rather than volume. NCCS served on several important committees of the National Quality Forum that review and approve quality measures. NCCS partnered with the National Committee for Quality Assurance on a project, funded by the Patient-Centered Outcomes Research Institute (PCORI), to evaluate the patient-centered medical home model for oncology. We continue to advocate for improving cancer care through the implementation of the Oncology Care Model by the Center for Medicare and Medicaid Innovation (CMMI).



03

Cancer Moonshot

NCCS participated in a working group that advised the Blue Ribbon Panel as part of Vice President Biden’s Cancer Moonshot. NCCS was pleased that one of the Panel’s recommendations included supporting symptom management research to minimize the debilitating side effects of cancer treatment.





Impacting Policy.





Promoting Advocacy.



NCCS' Cancer Policy and Advocacy Team (CPAT) Symposium and Hill Day in Washington, D.C., was a tremendous success. Advocates from across the country attended two days of informative presentations and discussions on cancer policy and advocacy.



The event culminated with advocates going to Capitol Hill and speaking with their Members of Congress and their staffs about the importance of survivorship and urging Members to support the Planning Actively for Cancer Treatment (PACT) Act.

We also hosted webinars for CPAT members about timely topics. One was titled, “A Conversation Around Shared Decision-Making and a Patient Revolution—and the Role of the PACT Act,” where Victor M. Montori, MD, MSc, discussed shared decision-making and Adriane Casalotti, deputy chief of staff for Congresswoman Lois Capps of California, spoke about the PACT Act. Another webinar NCCS hosted was titled, “Social Media Strategies for Patient Advocates,” and shared best practices for various social media platforms to help advocates increase their impact at the local and federal levels.

The Planning Actively for Cancer Treatment (PACT) Act would encourage the development of a personalized cancer care plan for Medicare beneficiaries.

- Help cancer patients through the difficult process of cancer diagnosis, treatment choices, treatment management, and survivorship care by supplying them with a written plan or roadmap.
- Encourage a shared decision-making process between patients and their cancer care teams.
- Support informed decision-making as treatment choices become increasingly complex.
- Empower the patient with tools to manage care from active treatment through long-term survivorship.



Financials.

Statement of activities and changes in net assets for the year ended December 31, 2016

	2016
REVENUE	
TOTAL REVENUE	\$2,115,706
EXPENSES	
TOTAL EXPENSES	\$2,096,350
CHANGE IN NET ASSETS	\$19,356
NET ASSETS (BEGINNING OF YEAR)	\$870,827
NET ASSETS (END OF YEAR)	\$890,183

The 2016 numbers represented above are preliminary and are subject to change upon audit.



National Coalition for Cancer Survivorship statement of financial position December 31, 2016



2016

CURRENT ASSETS

TOTAL CURRENT ASSETS	\$721,366
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OTHER ASSETS

TOTAL OTHER ASSETS	\$541,264
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TOTAL ASSETS

\$1,262,630

CURRENT LIABILITIES

TOTAL CURRENT LIABILITIES	\$372,447
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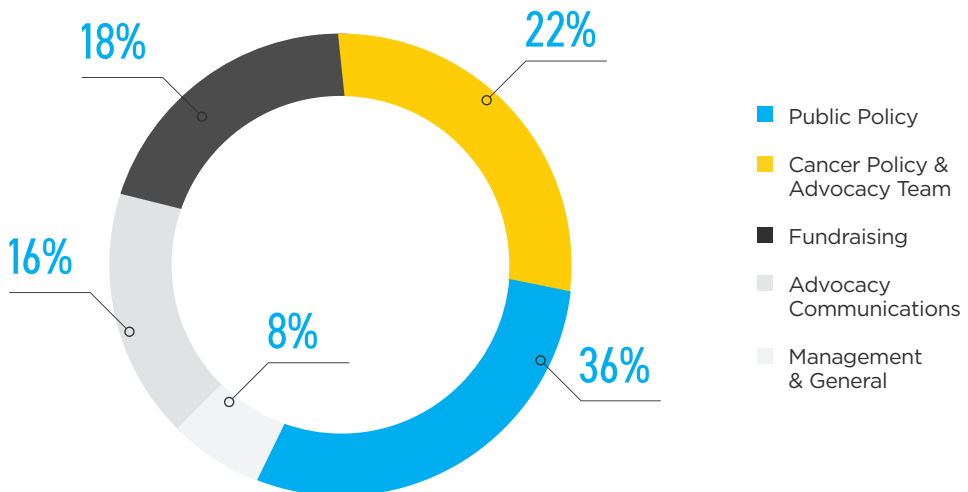
NET ASSETS

TOTAL NET ASSETS	\$890,183
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TOTAL LIABILITIES AND NET ASSETS

\$1,262,630

EXPENSES AT A GLANCE



Board Members.



Chair
**Lyman (Sandy)
Welton**



**Michael
Kappel**



**Samira
Beckwith**



**Jennifer
McGihon**



**Barbara
Hoffman**



**Eleanor
Winter**



**Laurie
Isenberg**

 **Cancer Survivor**

Policy Advisors.

Gregory J. Aune, MD, PhD

University of Texas Health Science Center,
San Antonio

Therese M. Mulvey, MD, FASCO

Massachusetts General Hospital

Stuart M. Butler, PhD

Brookings Institution

Lee Newcomer, MD

UnitedHealthcare

John V. Cox, DO

Parkland Hospital

Kevin C. Oeffinger, MD

Duke Cancer Institute

Bob Erwin

Marti Nelson Cancer Foundation

Ann H. Partridge, MD, MPH

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Scott Gottlieb, MD

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Strategic Oncology Consultants

Michael Link, MD

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Joshua M. Sharfstein, MD

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Jennifer Malin, MD

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Thomas Smith, MD

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Mary McCabe, RN, MN

Memorial Sloan-Kettering Cancer Center

Jennifer S. Temel, MD

Massachusetts General Hospital

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Jane and Jeff Bulman
C. Norman and Karolynn
Coleman
Kite Pharma
Kate Ditzler
Lucinda N. Dudley
Patricia Ganz, MD
Danielle Hatfield
Fitzhugh Mullan, MD and
Irene Dankwa-Mullan, MD
Therese M. Mulvey, MD
Shelley and Michael Nasso
National Committee for Quality
Assurance
National Patient Advocate
Foundation
Lynn Nye
Corinne B. Roberts
Robert Sachs
Leslie Seeman
The John A. Hartford
Foundation, Inc.
The Original Pancake House
Steven C. Thorntol
Susan L. Weiner

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Carol L. Alter
Barbara J. Barea
Ronald Berenstain
Lezley Blair
Michael G. Cunningham
Debra Curtis
Christin L. Engelhardt
Susan K. Fisher
Maureen Golden
Beverly R. Greenfeig
Miles Haber
Sheila Handel
Richard Hoffstein
Barbara L. Kerxton
Neil Kishter
Stephen Lewis and
Alison Wylegala
Alexandra G. Lucy
Liza Lucy
Barbara Maddox
Jennifer Malin
Jennifer McGihon
Tucker L. Melancon
Oncology Nursing Society
Sarah Scholle
Jerome Seidenfeld B100
Catherine D. Sevier
David M. Sevier
Yogendra Sheth
Mark Shostak
Ronald Snodgrass
Joseph W. Waz
Cynthia Young
Robert C. Young
Gary L. Zahrbock



This is the way cancer survivors

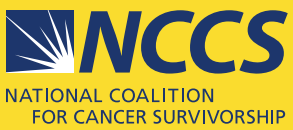
What most people diagnosed with cancer don't understand is that oncologists and their patients understand the importance of those treatments and how they should be used. As the population of survivors grows exponentially, it's important to focus on bringing new therapies forward to treat the long-term consequences of those treatments is part of

world of survivorship...

er want is to be cured of the cancer itself; what few
nd or even want to discuss are the consequences of
e managed. This is the world of cancer survivorship, and
tially every day, in large part because of the improvement
ur cancer. Knowing there are short- and long-term
f the planning for survivorship that must begin at diagnosis.

Ellen L. Stovall

Blog post for National Cancer Survivors Day in 2015



8455 Colesville Road
Suite 930
Silver Spring, MD 20910

