30 Years
Our Mission Continues...
2016 Annual Report
NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP
We advocate for quality cancer care for all individuals touched by cancer.
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

2016 marked the 30th anniversary of the National Coalition for Cancer Survivorship (NCCS).
“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.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Number of times Jen was misdiagnosed with Metastatic Breast Cancer.</td>
</tr>
<tr>
<td>02</td>
<td>Years of no evidence of disease.</td>
</tr>
<tr>
<td>05</td>
<td>Years of treatment she endured.</td>
</tr>
<tr>
<td>05</td>
<td>Months old her son was when she was misdiagnosed.</td>
</tr>
<tr>
<td>07</td>
<td>Number of doctors/specialists on her care team she had to coordinate.</td>
</tr>
<tr>
<td>80</td>
<td>Number of combined treatments she underwent.</td>
</tr>
<tr>
<td>$1M</td>
<td>Cost of her care to date.</td>
</tr>
</tbody>
</table>

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.
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
Transforming Care.
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.”
Cancer Policy Roundtables

NCCS hosted its 16th year of semi-annual Cancer Policy Roundtable (CPR) “think tank” meetings, convening stakeholders to discuss healthcare 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 healthcare policy moving forward.

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).

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

<table>
<thead>
<tr>
<th></th>
<th>2016</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REVENUE</strong></td>
<td></td>
</tr>
<tr>
<td>TOTAL REVENUE</td>
<td>$2,115,706</td>
</tr>
<tr>
<td><strong>EXPENSES</strong></td>
<td></td>
</tr>
<tr>
<td>TOTAL EXPENSES</td>
<td>$2,096,350</td>
</tr>
<tr>
<td><strong>CHANGE IN NET ASSETS</strong></td>
<td>$19,356</td>
</tr>
<tr>
<td>NET ASSETS (BEGINNING OF YEAR)</td>
<td>$870,827</td>
</tr>
<tr>
<td>NET ASSETS (END OF YEAR)</td>
<td>$890,183</td>
</tr>
</tbody>
</table>

The 2016 numbers represented above are preliminary and are subject to change upon audit.
EXPENSES AT A GLANCE

- Public Policy: 22%
- Cancer Policy & Advocacy Team: 18%
- Fundraising: 16%
- Advocacy Communications: 8%
- Management & General: 36%

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

<table>
<thead>
<tr>
<th>ASSET CATEGORY</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL CURRENT ASSETS</td>
<td>$721,366</td>
</tr>
<tr>
<td>OTHER ASSETS</td>
<td>$541,264</td>
</tr>
<tr>
<td>TOTAL ASSETS</td>
<td>$1,262,630</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITY CATEGORY</th>
<th>AMOUNT</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL CURRENT LIABILITIES</td>
<td>$372,447</td>
</tr>
<tr>
<td>NET ASSETS</td>
<td>$890,183</td>
</tr>
<tr>
<td>TOTAL LIABILITIES AND NET ASSETS</td>
<td>$1,262,630</td>
</tr>
</tbody>
</table>
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

Stuart M. Butler, PhD
Brookings Institution

John V. Cox, DO
Parkland Hospital

Bob Erwin
Marti Nelson Cancer Foundation

Scott Gottlieb, MD
American Enterprise Institute

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

Michael Kolodziej, MD
Flatiron Health

Michael Link, MD
Stanford Cancer Institute

Jennifer Malin, MD
UnitedHealthcare

Mary McCabe, RN, MN
Memorial Sloan-Kettering Cancer Center

Therese M. Mulvey, MD, FASCO
Massachusetts General Hospital

Lee Newcomer, MD
UnitedHealthcare

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

Jennifer S. Temel, MD
Massachusetts General Hospital
PREMIER SPONSOR
Amgen
Bristol-Myers Squibb Company
Eisai, Inc.
Genentech, Inc.
Lilly USA, LLC
Merck
Novartis Pharmaceuticals Corporation
Pfizer, Inc.

BENEFACTOR SPONSOR
Astellas Pharmaceuticals
Boehringer Ingelheim
Pharmaceuticals Inc.
Jazz Pharmaceuticals, Inc.
Takeda Oncology

PATRON SPONSOR
AbbVie Inc.
Bayer HealthCare LLC
Celgene Corporation
Johnson & Johnson Healthcare Inc.
Pharmaceutical Research & Manufacturers of America

SUSTAINING SPONSOR
Biotechnology Industry Organization
Taiho Oncology, Inc.

SUPPORTING SPONSOR
American Society of Clinical Oncology
Anthem, Inc.
Helsinn Therapeutics, Inc.
Stubblefield Foundation Inc.
TESARO, Inc

ASSOCIATE SPONSOR
Carolinas Healthcare System
Combined Federal Campaign
Daniel A. Mica, LLC
David Katz Foundation
Foundation for the Carolinas
Laurie Isenberg and Joel Roos
Musa Mayer
John Rakoske
Turner & Goss LLP
Eleanor Winter and Dan Backo
ZD Wines

PLATINUM SURVIVORS’ CIRCLE
Andrea and Mitchell Becker
iHeartMedia Management Services, Inc.
Julia H. Rowland, PhD

GOLD SURVIVORS’ CIRCLE
American Society for Radiation Oncology
Samira K. Beckwith
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. Thornton
Susan L. Weiner

SILVER SURVIVORS’ CIRCLE
Carolyn Aldige
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
Alexandra G. Lucy
Liza Lucy
Barbara Maddox
Jennifer Malin
Jennifer McGihon

TARADO, Inc.

SILVER SURVIVORS’ CIRCLE
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
What most people diagnosed with cancer want is to be cured of the cancer itself; what few oncologists and their patients understand or even want to discuss are the consequences of those treatments and how they should be managed.

This is the world of cancer survivorship, and that population of survivors grows exponentially every day, in large part because of the improvement in bringing new therapies forward to treat our cancer. Knowing there are short- and long-term consequences of those treatments is part of the planning for survivorship that must begin at diagnosis.

"This is the world of cancer survivorship..."
What most people diagnosed with cancer want is to be cured of the cancer itself; what few
don’t even want to discuss are the consequences of being managed. This is the world of cancer survivorship, and
initially every day, in large part because of the improvement in our cancer. Knowing there are short- and long-term
risks of the planning for survivorship that must begin at diagnosis.

Ellen L. Stovall
Blog post for National Cancer Survivors Day in 2015