

NCCS 2017 ANNUAL REPORT



NATIONAL COALITION
FOR CANCER SURVIVORSHIP



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

Dear Friends,

In 2017, the National Coalition for Cancer Survivorship (NCCS) continued our three decades of advocacy to transform cancer care for everyone touched by cancer. We held our seventeenth year of Cancer Policy Roundtable meetings, bringing together thought leaders from throughout the health care system to discuss critical issues vital to improving cancer care. We expanded our Cancer Policy and Advocacy Team (CPAT) program, culminating with over 60 patient advocates from across the country coming to Washington, D.C. for a symposium and over 120 meetings with Members of Congress. I am also proud to say we continued to grow the Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care. The strength of the applications made choosing one winner impossible, and the Selection Committee chose two incredible champions for patients: Pat Coyne, MSN, from the Medical University of South Carolina and Meg Gaines, JD, LLM, from the University of Wisconsin, Madison.

We also spent a considerable amount of time protecting the Affordable Care Act (ACA) from Congressional efforts to repeal the legislation. NCCS is a strong supporter of the ACA, as the law offers unprecedented personal, medical, and financial protections, allowing cancer patients, survivors, and their families some semblance of peace of mind that they never had before. We helped organize and lead our grassroots and other patient organizations in opposition to several proposals to repeal the ACA, all of which would have resulted in millions of Americans losing health care coverage, premium costs skyrocketing, and protections being eroded, threatening cancer patients and their families. While these bills were thankfully defeated in Congress, efforts continue to undermine the ACA through other means.

Our advocacy on behalf of patients is now more important than ever. Thank you for your continued support of NCCS, as we transform the health care system for all touched by cancer.

Sincerely,



Shelley Fuld Nasso, MPP
Chief Executive Officer

NCCS policy priorities



Care planning and coordination



Access to affordable, quality healthcare



Care that incorporates patient's goals and values



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




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


Yvonne



“Sharing our cancer experience as survivors is critical if we’re to improve and protect access to affordable, quality health care. NCCS continues to be an incredible resource to give me the skills and opportunities to make a difference through advocacy.”



Diagnosed at 50 with breast cancer, Yvonne became determined to support women who are diagnosed, being treated, and living with breast cancer. In doing so she established Sisters R Us Circle of Survivors, which aims to give financial support, provide survivorship resources, connect survivors with other patient advocacy organizations, and promote mammograms for underserved women.



Yvonne has been a Cancer Policy & Advocacy Team member for two years and this year she has made the most of it. Yvonne does not sit on the sidelines. Due to her proactive nature, we were happy to help nominate her to the American Association for Cancer Research (AACR) Scientist-Survivor Program, which allowed her to present a poster at the Science of Cancer Health Disparities Conference. In addition, she was selected to serve as a reviewer for the Peer Reviewed Cancer Research Program (PRCRP) of the Department of Defense (DOD) Congressionally Directed Medical Research Programs (CDMRP).

Perhaps the most important advocacy work Yvonne engaged in last year was the work to preserve the protections in the Affordable Care Act that are critical for cancer survivors. In addition to participating in the CPAT Symposium Hill Day, Yvonne returned home and submitted a press release about her advocacy experience, resulting in an article on the front page of her local newspaper. She continued to contact her Senators' offices to share a survivor's perspective throughout the ACA debate. Yvonne is an example of how much of an impact one person can make to protect cancer patients, both in her community and at the national level.

✦ Yvonne'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.

2017 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 two individuals to our board of directors:



Ben Fishman

Ben Fishman, a glioblastoma cancer survivor, joined the NCCS Board of Directors in March. He is a foreign policy and national security specialist who served at the White House from 2009-2013. Since his diagnosis, he has become incredibly active in the advocacy community in Washington, D.C., and he and his wife welcomed their first child in December.



Julia Rowland, PhD

Julia Rowland, PhD, joined the NCCS Board after serving 18 years as the Director of the National Cancer Institute's (NCI) Office of Cancer Survivorship (OCS). Dr. Rowland has been a long-time friend of NCCS, having previously been a member of the Board prior to her role at OCS. Her leadership has been instrumental to identifying and advancing our understanding of the complex issues that define survivorship.



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Hope**

www.canceradvocacy.org

Transforming Care.



NCCS continues its efforts to transform the delivery of cancer care by recognizing those who are leading the charge in this effort. This year, NCCS proudly awarded its second annual Ellen L. Stovall Award for Innovation in Patient-Centered Cancer Care to Pat Coyne, MSN, from the Medical University of South Carolina and Meg Gaines, JD, LLM, from the Center for Patient Partnerships at UW-Madison.

ng



Patrick Coyne

An advanced practice nurse, Pat has devoted his career to the advancement of the field of palliative care. Mr. Coyne is the Director of the Palliative Care Program at Medical University of South Carolina (MUSC). He is one of the founders of ELNEC (End-of-Life Nursing Education Consortium), which has educated more than 21,000 nurses in over 90 countries, and he has published over 100 papers on a variety of symptom management and policy issues.

Meg Gaines

Is a lawyer by training, a cancer survivor, and one of the founders of the Center for Patient Partnerships at the University of Wisconsin. The Center trains students in the fields of law, medicine, nursing, pharmacy, and social work to provide advocacy to cancer patients. Interdisciplinary teams help cancer patients understand their diagnoses, get the information necessary to make critical treatment decisions, and support patients' efforts to get the treatment they need.



Dr. Cliff Hudis, CEO of ASCO, speaks during a panel discussion on the role of biosimilars in cancer care.



Protecting Affordable, Quality Health Care

In 2017, NCCS worked tirelessly to help ensure cancer survivors' voices were consistently part of the health care discussion. As Congress made repeated attempts to repeal the Affordable Care Act (ACA), with health and financial protection cancer patients rely on in the balance, NCCS was a leader in opposing these harmful bills. NCCS brought dozens of cancer focused organizations together in several social media campaigns opposing repeal of the ACA and promoting bipartisan health care solutions that would strengthen the ACA.

As part of our grassroots efforts to protect the ACA, NCCS developed the "Protect Our Care" webpage, a one-stop location for advocates to get updates on health care reform efforts, with tools and ways to contact their Members of Congress. Along with the webpage, we launched a hotline where thousands of advocates throughout the United States called their Members of Congress to voice their opinion regarding attempts to repeal and replace the ACA.

NCCS also began hosting Facebook Live videos to provide advocates with updates on efforts to repeal or change the ACA. Thankfully, as 2017 came to an end, the ACA remained the law of the land though significantly weakened by administrative actions, and NCCS will continue these efforts to ensure cancer patients have access to quality and affordable health care.

Cancer Policy Roundtable

NCCS launched the seventeenth year of semi-annual Cancer Policy Roundtable "think tank" meetings with stakeholders from throughout the cancer community. Just a few months into the new administration, the Spring Roundtable focused on what the new political landscape in Washington meant for cancer patients and health care policy. Discussions included the impact of the 21st Century Cures Act, the future of the ACA, the role of biosimilars, and payment and delivery reform.

In November, NCCS hosted its Fall Cancer Policy Roundtable and we were honored to have Dr. Scott Gottlieb, commissioner of the Food and Drug Administration, as the opening keynote speaker. Informative panels continued throughout the day on a range of topics, including cost conversations between patients and oncologists, moving from volume to value, and appropriate testing to deliver targeted treatments.

We represent **16 million cancer patients and survivors** and the providers who care for them, and **we oppose ACA “repeal and delay”**.

32 million Americans would lose coverage and premiums would rise, making insurance unaffordable for cancer patients and survivors.

We ask the Senate to **vote NO on repeal and delay** and work together to improve health insurance.



Impacting Policy.



◀ FDA Commissioner Scott Gottlieb, MD, delivers opening keynote speech at our Fall Cancer Policy Roundtable.



Hill Day

On the third day, advocates went to Capitol Hill to meet with their elected officials. We were thrilled to start the day with cancer survivor Rep. Jamie Raskin (MD-8), whose thoughtful words inspired the advocates for the Hill Day ahead. Advocates and CUPID students spread out across Capitol Hill, asking Members to oppose the health care repeal bill that was being debated in the Senate.

SYMPOSIUM FEEDBACK:

"Mind blown. Thank you for this."

"I will use the information to keep in contact with my legislators, to keep in contact about the current political issues, and monitor next actions."

"I will use this information to help me as I advocate for other cancer patients and their families. I will also share the information with other survivors in hope that some may feel compelled to become an advocate as well."

NCCS continued to expand the Cancer Policy and Advocacy Team (CPAT) program, culminating with a two-day symposium, where CPAT members participated in panel discussions, interactive presentations, and breakout sessions.



HERE ARE SOME OF THE WAYS NCCS ENGAGES OUR CPAT MEMBERS:

- Facebook Live events
- Educational webinars
- Engagement opportunities
- Media opportunities
- Monthly e-newsletter

Promoting Advocacy.

Financials.

Statement of activities and changes in net assets for the year ended December 31, 2017

	2017
REVENUE	
TOTAL REVENUE	\$2,150,643
EXPENSES	
TOTAL EXPENSES	\$2,039,728
CHANGE IN NET ASSETS	\$110,915
NET ASSETS (BEGINNING OF YEAR)	\$890,183
NET ASSETS (END OF YEAR)	\$1,001,098

The 2017 numbers represented above are preliminary and are subject to change upon audit.



National Coalition for Cancer Survivorship statement of financial position December 31, 2017



2017

CURRENT ASSETS

TOTAL CURRENT ASSETS **\$634,590**

OTHER ASSETS

TOTAL OTHER ASSETS **\$746,526**

TOTAL ASSETS **\$1,381,116**

CURRENT LIABILITIES

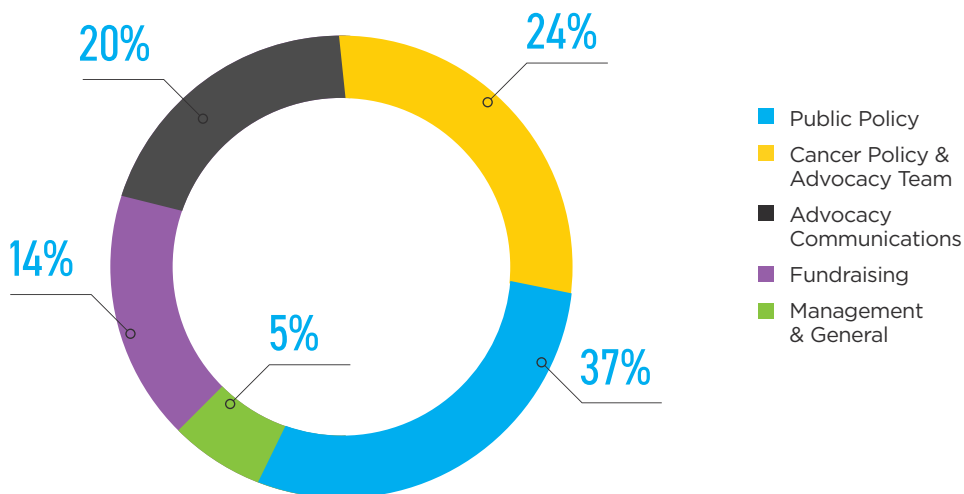
TOTAL CURRENT LIABILITIES **\$380,018**

NET ASSETS

TOTAL NET ASSETS **\$1,001,098**

TOTAL LIABILITIES AND NET ASSETS **\$1,381,116**

EXPENSES AT A GLANCE



◀ Shelley Fuld Nasso & Kelsey Nepote presented with Kate Houghton of Critical Mass at Stupid Cancer's CancerCon.



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◀ Shelley Fuld Nasso with Jeff and Jane Bulman, owners of the Original Pancake House restaurants, at a fundraising event to commemorate Ellen Stovall's birthday.

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**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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