Advocate Engagement at NCI

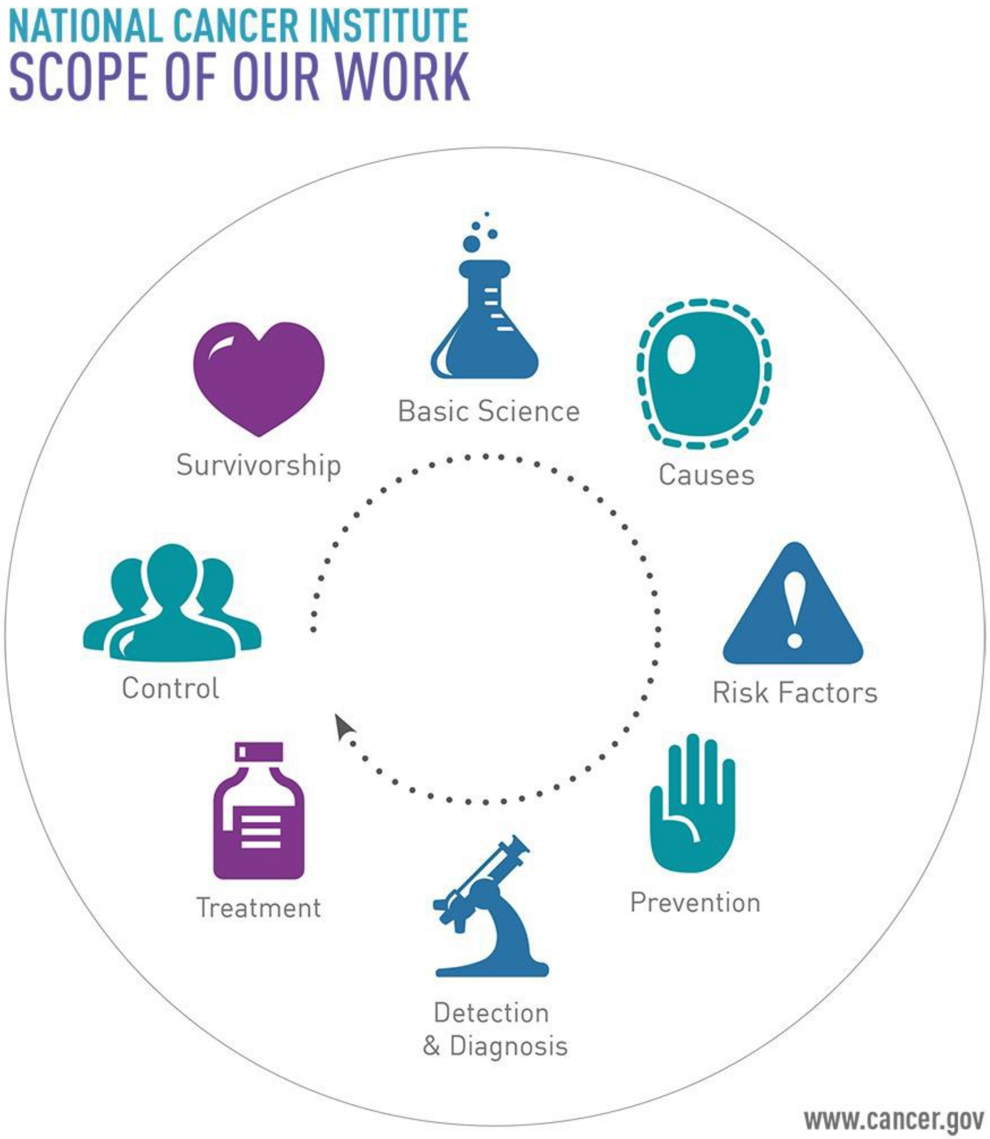
October 8th, 2019
NCI's Office of Advocacy Relations
Amy Williams, Director

NATIONAL CANCER INSTITUTE
Office of Advocacy Relations

NCI’s History

- The National Cancer Institute was established under the National Cancer Institute Act of 1937. In 1944, NCI was made an operating division of the National Institute of Health, as it was known then. NCI is the largest of the 27 institutes and centers at NIH.
- The National Cancer Act of 1971 broadened the scope and responsibilities of the NCI and created the **National Cancer Program**.

NCI’s Work


NATIONAL CANCER INSTITUTE
SCOPE OF OUR WORK
Basic Science
Causes
Risk Factors
Prevention
Detection & Diagnosis
Treatment
Control
Survivorship
www.cancer.gov

“Research advocates play a vital role in shaping NCI’s work. They challenge us, and ensure that we never lose sight of what we are here to do – which is to improve patient outcomes by advancing cancer research. We can’t do this without the unique perspectives research advocates bring.”

– Dr. Douglas Lowy,
Acting Director, NCI

Office of Advocacy Relations (OAR)

As part of NCI’s Office of the Director, OAR coordinates meaningful engagement across the cancer research advocacy community **to improve understanding, opportunity, and progress in cancer research.**

Communicate

Facilitate

Collaborate

Our Partners

Two-way communication with OAR’s network of advocates and advocacy organizations is vital in maintaining the culture of advocate engagement at NCI. Our audience includes:

Individual Research Advocates

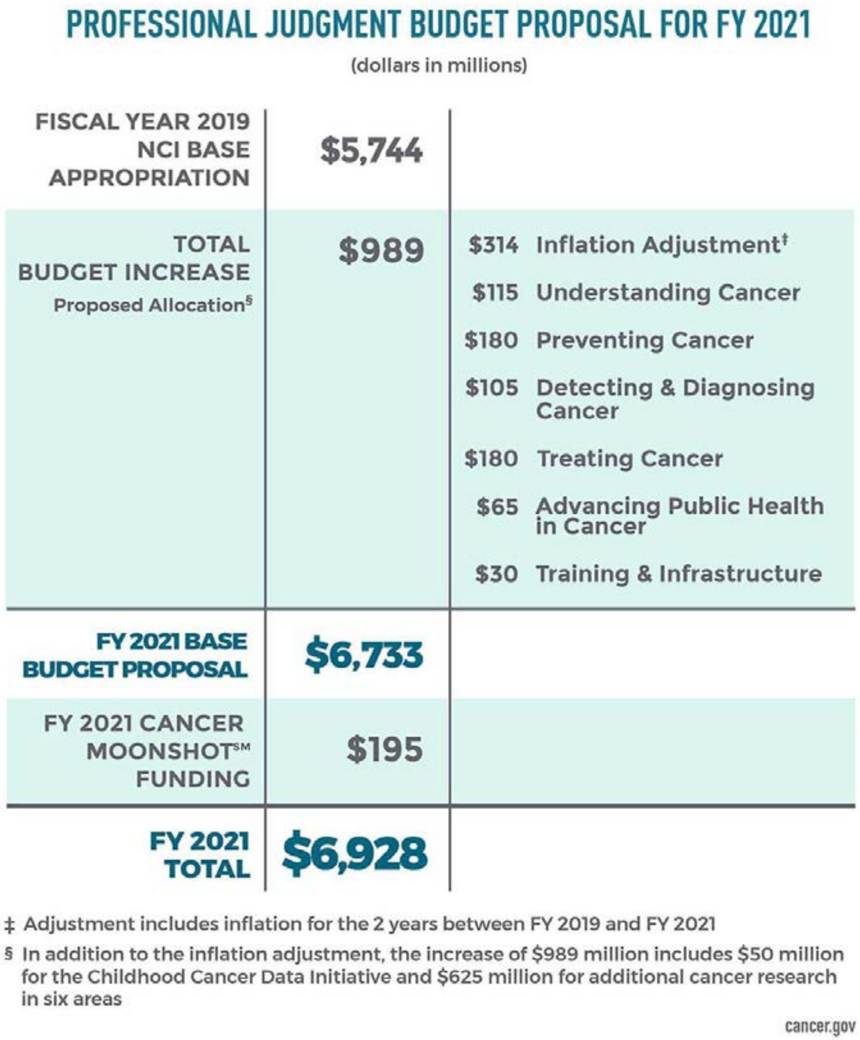
- OAR manages a network of over **250** active advocates spanning cancer types and geographic regions.
- **20** of these advocates were new in 2018.

Advocacy Organizations

- OAR works with advocacy organizations **ranging in size and focus** including organizations focused on a specific cancer type, coalitions, and survivorship groups.

Collaborating with the Advocacy Community

OAR works with **organizations, foundations, coalitions, and other groups** across the community to **advance understanding of policy, partnerships, and strategic investments** in cancer research.



PROFESSIONAL JUDGMENT BUDGET PROPOSAL FOR FY 2021

(dollars in millions)

FISCAL YEAR 2019 NCI BASE APPROPRIATION	$5,744		
TOTAL BUDGET INCREASE Proposed Allocation[§]	$989	$314	Inflation Adjustment[‡]
		$115	Understanding Cancer
		$180	Preventing Cancer
		$105	Detecting & Diagnosing Cancer
		$180	Treating Cancer
		$65	Advancing Public Health in Cancer
		$30	Training & Infrastructure
FY 2021 BASE BUDGET PROPOSAL	**$6,733**		
FY 2021 CANCER MOONSHOT℠ FUNDING	$195		
FY 2021 TOTAL	**$6,928**		

[‡] Adjustment includes inflation for the 2 years between FY 2019 and FY 2021

[§] In addition to the inflation adjustment, the increase of $989 million includes $50 million for the Childhood Cancer Data Initiative and $625 million for additional cancer research in six areas

cancer.gov

Collaborating with the Advocacy Community (cont.)

OAR works with individual research advocates by:

- serving as conduit between the cancer advocacy community and NCI research and program staff
- ensuring advocates are positioned for success and prepared to add value to NCI's work
- recommending creative solutions for advocate engagement at NCI

ADVISORY BOARDS • MATERIALS REVIEW • PLANNING COMMITTEES
PEER REVIEW • STEERING COMMITTEES • USABILITY TESTING • AND MORE!

Office of Advocacy Relations
Learn more at advocacy.cancer.gov

How We Connect Advocates and NCI

Keeping advocates engaged requires a mix of proactively communicating NCI's priorities and initiatives to the community and responding to inquiries and concerns from advocates and organizations.

- ***News digest/ Listserv notices*** – In addition to receiving timely email announcements and event invitations, **1,000+** subscribers to the Listserv receive a **monthly digest** updating them on the latest NCI news, events, and research.
- ***Webinars*** – **Orientation webinars** are held to onboard new advocates, while topic-specific webinars are held to educate advocates on a broad range of topics. Examples of OAR hosted webinars include **National Coverage Analyses for NCI Network Clinical Trials** and **NCI's Scientific Peer Review Process**
- ***Meetings*** – OAR convenes meetings with advocates and NCI staff throughout the year to make sure the collective patient perspective is heard.
- ***Phone Calls*** – The OAR office fields regular calls with advocates or organizations to discuss issues relevant to NCI.

Meetings Convened with Organizations

OAR regularly engages with organizations in the advocacy space and other federal partners. In 2018, OAR set up meetings with the following:

- Alliance for Childhood Cancer
- American Association for Cancer Research
- American Brain Tumor Association
- American Cancer Society
- American Cancer Society Cancer Action Network
- Cancer Support Community
- Cervivor
- Coalition Against Childhood Cancer
- Deadliest Cancers Coalition
- Debbie's Dream Foundation
- Eliminate Cancer Initiative
- Esophageal Cancer Action Network
- Fight Colorectal Cancer
- Global Down Syndrome Foundation
- International Kidney Cancer Coalition
- International Neuroendocrine Cancer Alliance
- Lambs for Life Foundation
- Leukemia and Lymphoma Society
- Lung Cancer Alliance
- Lymphatic Education and Research Network
- METAvivor
- Representatives from Navajo Nation
- No Stomach for Cancer
- Ovarian Cancer Research Alliance
- Pancreatic Cancer Action Network
- Susan G. Komen Foundation
- St. Baldrick's Foundation

Research Advocates at NCI

- Have prior involvement in cancer research-related activities
- Have personal experience with cancer due to their own diagnosis, or are connected to someone who has been diagnosed with cancer
- Convey a collective patient perspective
- Are comfortable interacting with diverse audiences in person, over the phone, and/or in writing

Advocates and Clinical Trials

- NCI's Council of Research Advocates (NCRA) – Federal Advisory Committee comprised solely of cancer research advocates

- National Clinical Trials Network (NCTN) – externally funded network responsible for clinical trials, including precision medicine portfolio

- Scientific Steering Committees and Task Forces – guide for NCI's clinical trial enterprise

- Division of Extramural Activities (DEA) – Division responsible for extramurally funded research

- Clinical Trials and Translational Research Advisory Committee (CTAC) – external oversight committee that advises NCI on it's clinical and translational portfolios.

Common Areas for Advocate Input within our Clinical Trials Network

- Portfolio analysis
- Informed consent
- Eligibility criteria
- Study design
- Patient-facing materials
- Recruitment strategies
- Outcome data
- Data Safety and Monitoring Boards*
- Dissemination

Goal & Purpose of the Scientific Steering Committees

- The Scientific Steering Committees (SSCs) were created to guide ***NCI's Clinical Trials Enterprise***

- SSCs are composed of leading cancer experts, advocates from outside the Institute as well as NCI senior investigators who meet regularly to:

    - Evaluate clinical trial concepts and set disease specific strategic priorities

    - Increase community involvement in clinical trial design and prioritization

    - Evaluate & provide input into design and implementation of clinical trial concepts

    - Patient advocates are voting members

NCI’s Council of Research Advocates

- The NCRA focuses on matters that facilitate research and often identifies and responds to challenges facing the Institute at the request of NCI leadership.

- The NCRA focuses on enhancing community input, optimizing community outreach, and promoting strong collaborations to improve research outcomes.

Thank you!

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