

2024 Current Fiscal Year Report: National Cancer Institute Council of Research Advocates

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1. Department or Agency

Department of Health and Human Services

2. Fiscal Year

2024

3. Committee or Subcommittee

National Cancer Institute Council of Research Advocates

3b. GSA

Committee No.

5248

4. Is this New During Fiscal Year?

No

5. Current Charter

08/17/2022 08/17/2024

6. Expected Renewal Date

7. Expected Term Date

8a. Was Terminated During Fiscal Year?

No

8b. Specific Termination Authority

8c. Actual Term Date

9. Agency

Recommendation for Next Fiscal Year

Continue

10a. Legislation Req to Terminate?

Not Applicable

10b.

Legislation Pending?

Not Applicable

11. Establishment Authority Authorized by Law

12. Specific Establishment Authority

42 U.S.C. 285a-2(b)(7)

13. Effective Date

11/20/1985

14. Committee Type

Continuing

14c. Presidential?

No

15. Description of Committee Scientific Technical Program

Advisory Board

16a. Total Number of Reports

No Reports for this Fiscal Year

17a. Open

0

17b. Closed

0

17c. Partially Closed

0

Other Activities

0

17d. Total

0

Meetings and Dates

No Meetings

| | Current FY | Next FY |
|---|---------------|------------|
| 18a(1). Personnel Pmts to Non-Federal Members | \$0.00 | \$0.00 |
| 18a(2). Personnel Pmts to Federal Members | \$0.00 | \$0.00 |
| 18a(3). Personnel Pmts to Federal Staff | \$0.00 | \$0.00 |
| 18a(4). Personnel Pmts to Non-Member Consultants | \$0.00 | \$0.00 |
| 18b(1). Travel and Per Diem to Non-Federal Members | \$0.00 | \$0.00 |
| 18b(2). Travel and Per Diem to Federal Members | \$0.00 | \$0.00 |
| 18b(3). Travel and Per Diem to Federal Staff | \$0.00 | \$0.00 |
| 18b(4). Travel and Per Diem to Non-member Consultants | \$0.00 | \$0.00 |
| 18c. Other(rents,user charges, graphics, printing, mail, etc.) | \$0.00 | \$0.00 |
| 18d. Total | \$0.00 | \$0.00 |
| 19. Federal Staff Support Years (FTE) | 0.00 | 0.00 |

20a. How does the Committee accomplish its purpose?

The role the National Cancer Institute's Council of Research Advocates (NCRA) is to identify and respond to issues and challenges facing the Institute and the cancer research community, at the request of the NCI Director. Board members provide informed, non-scientific perspectives relevant to promoting research outcomes that are in the best interest of patients. This includes identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI or other federal government

decisions or actions, as well as enhancing input, optimizing outreach, and promoting strong collaborations, all with respect to non-scientist stakeholders, in the interest of meeting common Institute and community goals. In FY2023, NCRA held one in-person/hybrid meeting on March 1, 2023 and one virtual meeting on June 21, 2023. Members were provided updates from the NCI Director; updates from the NCI Deputy Director; updates on budgetary and legislative matters; updates on NCI's Clinical Trials Programs and NCI's Patient-Derived Models Repository; an update on the Advanced Research Projects Agency for Health (ARPA-H); an update on NCI's Clinical Trials Innovation Unit (CTIU); and an update on opportunities to achieve Cancer Moonshot goals before providing their thoughts, insights, and observations to the NCI Director and other senior leaders.

20b. How does the Committee balance its membership?

The Committee consists of up to 16 members, including the Chair appointed by the Director, NCI. The membership consists of cancer research advocates who are involved in the cancer experience and possess an expert understanding of non-scientific burdens to cancer research as well as of the perspectives and dynamics of the research, patient, policy, and advocacy communities interested in cancer research and cancer care delivery. This expert understanding will have been gained through experience working in the cancer advocacy field, affiliation with a cancer related professional society, affiliation with a research foundation involved in cancer research or healthcare, experience as a health care professional focused on the study of cancer and other related diseases, or experience serving as a

thought-leader in an area related to cancer research and care delivery.

20c. How frequent and relevant are the Committee Meetings?

Meetings of the full Committee will be held approximately 2-3 times within a fiscal year. The Committee met two times during this reporting period to advise and make recommendations to the Director and NCI leadership, from the perspective and viewpoint of cancer research advocates on a wide variety of issues, programs, and research priorities. In FY2023, the NCRA meetings were held on March 1, 2023 (in-person/hybrid) and June 21, 2023 (virtual).

20d. Why can't the advice or information this committee provides be obtained elsewhere?

The membership consists of cancer research advocates who possess an expert understanding of non-scientific burdens related to cancer research, as well as of the perspectives and dynamics of the research, patient, policy, and advocacy communities interested in cancer research and cancer care delivery. The advice is not available from NCI staff or existing committees.

20e. Why is it necessary to close and/or partially closed committee meetings?

N/A

21. Remarks

Reports: This committee did not produce any public reports. Max Number of Members Total: The Charter allows the Committee to have up to 16 authorized members including the chair. There are currently 14 SGEs. Vacancies/On-Boarding: The committee has two vacancies and three

members were on-boarded [Brittany Avin McKelvey, Marty Chakoian, and Robert Riter]. This is why the Charter states up to 16 members, but this ACR lists 14. Members: The terms for Yelak S. Biru, Kristen C. Santiago, and Nicole E. Willmarth have changed due to reappointments. As such, their term end dates are different than what was reported in FY22. The DFO and Committee Decision Maker positions are held by the same individual because of the assignment of responsibilities within the Institute.

Designated Federal Officer

AMY WILLIAMS ACTING DIRECTOR, OFFICE OF ADVOCACY RELATIONS

| Committee Members | Start | End | Occupation | Member Designation |
|-------------------------------|--------------|------------|--|--|
| AVIN McKALVEY, BRITTANY | 11/06/2022 | 06/30/2026 | SCIENCE POLICY ANALYST, FRIENDS OF CANCER RESEARCH | Special Government Employee (SGE) Member |
| BACHINI, MELINDA | 09/13/2020 | 06/30/2024 | ADVOCACY COORDINATOR, CHOLANGIOCARCINOMA FOUNDATION | Special Government Employee (SGE) Member |
| BIRU, YELAK | 05/26/2020 | 06/30/2024 | CHIEF EXECUTIVE OFFICER, INTERNATIONAL MYELOMA FOUNDATION | Special Government Employee (SGE) Member |
| BUENGER, VICTORIA | 11/21/2021 | 06/30/2025 | PRESIDENT EMERITUS, COALITION AGAINST CHILDHOOD CANCER | Special Government Employee (SGE) Member |
| BUFFALO, MELISSA | 02/13/2022 | 06/30/2025 | CHIEF EXECUTIVE OFFICER, AMERICAN INDIAN CANCER FOUNDATION | Special Government Employee (SGE) Member |
| CHAKOIAN, MARTY | 02/12/2023 | 06/30/2026 | BOARD OF DIRECTORS, ZERO PROSTATE CANCER | Special Government Employee (SGE) Member |

| | | | |
|----------------------|------------|------------|---|
| ELLIS, ANNIE | 08/31/2020 | 06/30/2024 | RESEARCH ADVOCATE, Special GYNECOLOGIC CANCER Government STEERING COMMITTEE, Employee OVARIAN CANCER (SGE) RESEARCH ALLIANCE Member |
| FERRE, NATHANIEL | 09/25/2022 | 06/30/2026 | ASSOCIATE Special CONSULTANT, CHARTIS Government ONCOLOGY SOLUTIONS Employee (SGE) Member |
| HARRIS, JOYA | 09/25/2022 | 06/30/2026 | EXECUTIVE DIRECTOR, Special CEO ROUNDTABLE ON Government CANCER Employee (SGE) Member |
| RITER, ROBERT | 11/06/2022 | 06/30/2026 | PATIENT ADVOCATE, Special PHYSICAL SCIENCES Government ONCOLOGY CENTER, Employee CORNELL UNIVERSITY (SGE) Member |
| SANTIAGO, KRISTEN | 07/06/2020 | 06/30/2024 | SENIOR DIRECTOR, Special PUBLIC POLICY Government INITIATIVES, LUNGEVITY Employee (SGE) Member |
| SMITH, JACQUELINE | 11/23/2020 | 06/30/2024 | DIRECTOR OF PATIENT Special ADVOCACY, VERTEX Government PHARMACEUTICALS Employee (SGE) Member |
| STEMBERGER, KEVIN | 08/31/2020 | 06/30/2024 | RESEARCH ADVOCATE, Special CO-FOUNDER AND Government PARTNER, NOBLE Employee CAPITAL PARTNERS, (SGE) LLC Member |
| WILLMARTH, NICOLE | 05/26/2020 | 06/30/2024 | CHIEF MISSION Special OFFICER, AMERICAN Government BRAIN TUMOR Employee ASSOCIATION (SGE) Member |

Number of Committee Members Listed: 14

Narrative Description

The NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. The NCI Council of Research Advocates (NCRA), is the only federal advisory committee comprised of advocate leaders at

NCI. NCRA members are chosen for their expert knowledge of issues of importance to the cancer research community. The NCRA identifies and responds to issues and challenges facing the Institute and cancer research community and provides advice to the NCI Director around approaches to enhance community input, optimize community outreach, and promote effective collaborations that will help address these challenges and lead to improved research outcomes. In addition, NCRA members bring their unique skills and perspectives by identifying new approaches, promoting innovation, recognizing unforeseen risks or barriers, and identifying unintended consequences that could result from NCI decisions. The NCRA focuses on enhancing community input, optimizing community outreach, and promoting strong collaborations to improve research outcomes.

What are the most significant program outcomes associated with this committee?

Checked if
Applies

| | |
|---|-------------------------------------|
| Improvements to health or safety | <input type="checkbox"/> |
| Trust in government | <input checked="" type="checkbox"/> |
| Major policy changes | <input type="checkbox"/> |
| Advance in scientific research | <input type="checkbox"/> |
| Effective grant making | <input type="checkbox"/> |
| Improved service delivery | <input type="checkbox"/> |
| Increased customer satisfaction | <input checked="" type="checkbox"/> |
| Implementation of laws or regulatory requirements | <input type="checkbox"/> |
| Other | <input checked="" type="checkbox"/> |

Outcome Comments

Public engagement in the research process.

What are the cost savings associated with this committee?

Checked if Applies

| | |
|---------------------|-------------------------------------|
| None | <input type="checkbox"/> |
| Unable to Determine | <input checked="" type="checkbox"/> |
| Under \$100,000 | <input type="checkbox"/> |

| | |
|----------------------------|--------------------------|
| \$100,000 - \$500,000 | <input type="checkbox"/> |
| \$500,001 - \$1,000,000 | <input type="checkbox"/> |
| \$1,000,001 - \$5,000,000 | <input type="checkbox"/> |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/> |
| Over \$10,000,000 | <input type="checkbox"/> |
| Cost Savings Other | <input type="checkbox"/> |

Cost Savings Comments

NCI supports basic, translational and clinical research which often takes many years to deliver clinically applicable scientific advances.

What is the approximate Number of recommendations produced by this committee for the life of the committee?

99

Number of Recommendations Comments

In FY23, NCRA made general recommendations. The NCRA is an advisory committee designed to provide perspective, feedback, and ideas to the NCI. NCRA also provides a forum for government and private groups to work together to address critical issues that affect NCI's work.

What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

40%

% of Recommendations Fully Implemented Comments

The percentage of recommendations implemented as stated above were developed at the time the Annual Comprehensive Report was prepared.

What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?

40%

% of Recommendations Partially Implemented Comments

The percentage of recommendations implemented as stated above were developed at the time the Annual Comprehensive Report was prepared.

Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?

Yes ☒ No ☐ Not Applicable ☐

Agency Feedback Comments

E-mail updates and presentations at the meetings. NCI leadership gave feedback directly to the NCRA through meetings with the full advisory group. The NCI community is made aware of NCRA activities through NCI's Office of Advocacy Relations. Information is provided to the public at each meeting. The public can view information related to the Committee through the NCRA's official website.

What other actions has the agency taken as a result of the committee's advice or recommendation?

Checked if Applies

| | |
|-----------------------------------|-------------------------------------|
| Reorganized Priorities | <input type="checkbox"/> |
| Reallocated resources | <input type="checkbox"/> |
| Issued new regulation | <input type="checkbox"/> |
| Proposed legislation | <input type="checkbox"/> |
| Approved grants or other payments | <input type="checkbox"/> |
| Other | <input checked="" type="checkbox"/> |

Action Comments

The Committee makes recommendations to federal staff by responding to issues and challenges facing the Institute and cancer research community and provides advice to the NCI Director around approaches to enhance community input, optimize community outreach, and promote effective collaborations that will help address these challenges and lead to improved research outcomes. As a result, specific topics of interest to the cancer research advocacy community are defined and integrated into the NCI's Office of Advocacy Relations communications strategy and plan.

Is the Committee engaged in the review of applications for grants?

No

Grant Review Comments

N/A

How is access provided to the information for the Committee's documentation?

Checked if Applies

| | |
|------------------------|-------------------------------------|
| Contact DFO | <input checked="" type="checkbox"/> |
| Online Agency Web Site | <input checked="" type="checkbox"/> |

| | |
|---------------------------|-------------------------------------|
| Online Committee Web Site | <input checked="" type="checkbox"/> |
| Online GSA FACA Web Site | <input checked="" type="checkbox"/> |
| Publications | <input checked="" type="checkbox"/> |
| Other | <input checked="" type="checkbox"/> |

Access Comments

Information on the NCRA can be found at the NCI Division of Extramural Activities: Advisory Boards, Committees and Review Groups website at <http://deainfo.nci.nih.gov/advisory/ncra/ncra.htm>. Each NCI committee's charter, minutes, agenda, roster, future meeting dates, meeting PowerPoint presentations and reports is located here. Additionally, the public may view the NCRA meetings (both live and on demand) via the NIH Videocast at the following website: <http://videocast.nih.gov/>.