

# HEALTH RESEARCH ALLIANCE MEMBERS MEETING

November 19 – 20, 2025



**Sponsored by Conquer Cancer, the ASCO Foundation; The Alzheimer's Association; The Donaghue Foundation; Burroughs Wellcome Fund; and BrightFocus Foundation**

*The meeting will be held at the American Society of Clinical Oncology offices  
2318 Mill Rd #800, Alexandria, VA 22314*

*All sessions will be live streamed via Zoom unless otherwise noted*

## November 19 | Wednesday

**11:00am–12:00pm ET    Lunch and Registration**

**12:00pm–12:45pm ET    Welcome and Meet the Meeting Sponsors**

**12:45pm - 1:00pm ET    Break**

**1:00pm - 2:00pm ET    Navigating Shifts: Impact of Federal Policy Changes on the Biomedical Workforce**

Federal policy decisions shape the landscape of biomedical research and profoundly influence the careers, stability, and diversity of the scientific workforce. Ongoing shifts are particularly consequential for early career researchers and workforce development programs, which often serve as the entry points into scientific careers. Understanding and anticipating the effects of federal policy changes is critical for non-profit research funders in advancing their missions and sustaining long-term impact. This panel will bring together leaders from government, academia, and the non-profit sector to examine how changes in federal priorities, budgets, and regulations impact workforce development, talent pipelines, equity initiatives, and the broader research infrastructure.

### **Moderator**

**Diane Bovenkamp, PhD**

Vice President, Scientific Affairs | BrightFocus Foundation

### **Presenters**

**Sindy Escobar Alvarez, PhD**

Program Director for Medical Research | Doris Duke Foundation

**Bianca Frogner, PhD**

Professor and Interim Chair, Dept of Family Medicine Director | School of Medicine at University of Washington

**Alycia Halladay, PhD**

Chief Science Officer | Autism Science Foundation

**Jon Retzlaff, MBA, MPA**

Chief Policy Officer and Vice President, Science Policy and Government Affairs | American Association for Cancer Research

**2:00pm - 2:30pm ET    Break**

*(agenda continues on next page)*

2:30pm - 3:30pm ET

### **Lessons in Rare Diseases: Funding, Review, and Sustaining Efforts**

Rare disease research faces unique funding challenges—limited donor pools, few established researchers, and persistent gaps in scientific knowledge. This session explores creative funding strategies, from forging partnerships to leveraging non-traditional donors, insights into the proposal review process, and examines how to catalyze progress in under-resourced fields. We'll discuss how to support both established and new investigators, manage the small but passionate research communities, and connect funders—both within and outside the rare disease space—to impactful opportunities.

#### **Moderator**

**Elise Hoover, PhD**

Vice President of Research | Foundation for Sarcoidosis Research

#### **Presenters**

**Sara DiNapoli, PhD**

Director of Scientific Programs | Melanoma Research Alliance

**Barbara Goodman**

President and CEO | Cures within Reach

**Clare Thibodeaux, PhD**

Vice President of Scientific Affairs | Cures within Reach

**Tracey Sikora**

Vice President of Research and Clinical Programs | National Organization for Rare Disorders

3:30pm - 4:00pm ET

### **Break**

4:00pm - 5:00pm ET

### **Therapeutic Development Community Session - Not Just Funders: Nonprofits as Ecosystem Builders**

Bringing medical breakthroughs from labs to patients takes more than funding — it requires intentional strategies to build supportive communities, provide access to the right tools, and connect innovators with the resources they need. This session will explore how nonprofits are stepping into this broader role: protecting ideas, sparking connections, and accelerating progress through non-financial support. Join the discussion on what's working, and how organizations can drive even greater success.

#### **Speaker and Moderator**

**Abi Kulshreshtha, PhD**

Executive Director | Maryland Innovation Initiative

5:00pm - 7:00pm ET

### **Reception at the ASCO offices**

Hosted by [Altum](#)

## **November 20 | Thursday**

8:00am - 9:00am ET

### **Breakfast and Registration**

9:00am - 10:00am ET

### **Why are We Here? A reflection of and vision for biomedical research funding and philanthropic and non-profit involvement**

This session explores a historical view of how the biomedical research enterprise has been funded and how philanthropic and non-profit organizations fit into this enterprise. Speakers will address the advent of government support for science and its infrastructure in the United States along with how that research funding intertwines with the non-profit and for-profit sectors.

*(Session details continue on next page)*

The session will also explore the ways that philanthropic and non-profit organizations have led, supplemented, and influenced the biomedical research landscape. From the talks and discussion, participants will understand the overall structures for biomedical research funding, the history of how such structures came to be, and the role philanthropic and non-profit organizations fulfill in achieving beneficial impact for humankind.

**Moderator**

**Kaitlin Davis, PhD**

Director of Translational Sciences | Additional Ventures

**Presenters**

**Eric Abrahamson, PhD**

PI/Fellow, History of Science Philanthropy, Institute for Applied Economics, Global Health, and Study of Business Enterprise | Johns Hopkins University

*(session details continue on next page)*

**Victoria Harden, PhD**

Biomedical Sciences History Consultant, former Director | Office of NIH History and the Stetten Museum

**Carrie Patton**

National Senior Director of Research and Grants | American Heart Association

**10:00am - 10:30am ET**

**Break**

**10:30am - 11:30am ET**

**What's the Story? Making Science Funding Meaningful to the Public**

In today's rapidly shifting federal funding landscape, it is critical to be able to clearly articulate the importance of the need to fund innovative and transformative research, from basic science to translational and clinical research. Building public trust is one tool that may help enable more support for scientific research and ultimately lead to an increase in federal funding. This session explores how strategic storytelling can humanize research, highlight results, and connect with patients, caregivers, and the general public. Attendees will hear from a science journalist and a foundation representative on how to craft and share compelling narratives, and how to approach social media and public relations in a way that is most effective in our current climate.

**Moderator**

**David Leyden, MPA, CRA**

Vice President, Finance and Administration, SFARI, Neuroscience and Informatics | Simons Foundation

**Presenters**

**Siri Carpenter, PhD**

Executive Director and Editor-in-Chief | The Open Notebook

**Ekemini Riley, PhD**

Founder and CEO | Coalition for Aligning Science

**11:30am - 12:30pm ET**

**Lunch**

**12:30pm - 2:00pm ET**

**Professional Development Workshop: Storytelling for Impact**

In this interactive workshop, a professional facilitator will introduce participants to a robust framework for how to narrate and illustrate impact effectively. This framework will help participants learn how to develop compelling narratives for their specific audiences, craft an effective story arc, and understand the importance of ethical and asset-based storytelling.

**Facilitator**

**Luis Ortega, M.Ed.**

Director and Founder | Storytellers for Change

<b>2:00pm -2:30pm</b>	<b>Break</b>
<b>2:30pm -3:30pm ET</b>	<b>Research Workforce &amp; Early Career Development Learning Community Open Mic Discussion</b>
<b>3:30pm -4:00pm ET</b>	<b>Closing Remarks</b>