

HEALTH RESEARCH ALLIANCE MEMBERS MEETING AGENDA

April 13-16, 2026



*The meeting will be held entirely online via Zoom.
Please register for individual sessions at the links below.*

April 13 | Monday

1:30pm - 2:30pm ET

[Register here](#)

Welcome to the Members Meeting

Presenter

Christine Riordan, PhD

Executive Director | Health Research Alliance

Engaging and Partnering with Patients in Research Funding and Other Organizational Initiatives

This session will showcase concrete, case-based examples of how funders and research organizations meaningfully engage patients in research funding and other core initiatives, such as including patient advocates in peer review, forming patient advisory groups, and co-developing research projects. Speakers will walk through real initiatives, highlighting common challenges and demonstrated impact. An individual with lived experience will open the session with their experience participating in research.

Moderator

Carolyn Giannopoulos, MS

Research Grants Manager | American Brain Tumor Association

Speakers

Jennifer Brummet, PhD, CAE

Director, Scientific Affairs and Partnerships | CurePSP

Carol Chapman, MPH

Associate Director, Research Engagement | Crohn's & Colitis Foundation

Dwayne Taliaferro, PhD

Program Manager, Congressionally Directed Medical Research Programs (CDMRP) | United States Army

2:30pm-3:00pm ET

Break

April 13 | Monday (cont'd)

3:00pm-4:00pm ET
[Register here](#)

Advancing Research through CDISC-aligned Data Registries and Repositories

Patient registries and clinical data repositories are only as powerful as the data standards they leverage. Nicole Harmon, Chief Operating Officer at the Clinical Data Interchange Standards Consortium (CDISC) will share tools for turning fragmented registry and study data into interoperable, AI-ready research assets that can be reused across projects and platforms. Attendees will learn how CDISC collaborations may benefit their programs, whether the registry/biorepository they are involved with has been long running or is currently being designed. The session will also outline the near- and long-term benefits of investing in CDISC alignment, including reduced data harmonization effort, stronger collaborations with regulators and industry, and an elevated role as a leader in data-driven research and patient outcomes.

Moderator

Jerome Jourquin, PhD

Senior Director, Data Science | Susan G. Komen

Speakers

Nicole Harmon, PhD

Chief Operating Officer | Clinical Data Interchange Standards Consortium (CDISC)

April 14 | Tuesday

12:00pm-1:00pm
[Register here](#)

Defending Your Science: Communications Strategies for an Era of Misinformation and AI-Accelerated Noise

This professional development workshop will help members understand the full landscape of information threats facing biomedical research today — from AI-generated false content to misrepresented findings — and build organizational capacity to protect their funded science's credibility.

Attendees will walk away with a triage + response playbook they can adapt for their organization, including how to track threats, when to engage, how to correct the record effectively, and how to proactively build a credible information presence before a crisis hits.

Facilitators

Amanda Bevis, MPH, MBA, PMP

Senior Director | District Communications Group

Patrick McCarthy

Chief Delivery Officer | District Communications Group

April 14 | Tuesday (cont'd)

2:00pm-3:00pm ET
[Register here](#)

Open Mic: Peer Solutions for Your Research Grant Evaluation Challenges
Bring your research grant evaluation questions to this interactive, peer-driven clinic! In a supportive open-mic format, participants will have 5 minutes to present a real-world evaluation challenge they're facing. Each presentation will be followed by a 10-minute group discussion, where peers share their experiences, strategies, and creative solutions. We'll feature 3-4 mini-cases, leaving time for open Q&A. Whether you're stuck on data collection, reporting, stakeholder engagement, or something else—come ready to learn from and with your colleagues!

Facilitators

M. Brent Dolezalek

Vice President of Operations | James S. McDonnell Foundation

Jennifer Mortensen, PhD

National Director, Program Evaluation | American Heart Association

April 15 | Wednesday

1:00pm-2:00pm ET
[Register here](#)

Meeting the Moment: Managing the Surge in Grants Applications

Non-profit research funders are seeing unprecedented growth in grant submissions as needs of the research community rise and federal funding landscapes and priorities shift. This session will explore practical strategies for these organizations to manage increasing application volume while upholding fairness and scientific rigor. Panelists will discuss approaches to easing reviewer load, the responsible use of AI tools to support (not replace) human review, and when Letters of Intent (LOIs) can help reduce burden for both applicants and reviewers. The session will also explore how to refine program strategy amid growing demands for funding.

Moderator

David Leyden, MPA

Vice President, Finance and Administration | The Simons Foundation

Speakers

Jessica M. Biddinger, MS

National Senior Director, Research & Grants Administration | American Heart Association

Ryan Godfrey

Senior Manager of Research Programs | Cancer Research Institute

Samantha Lanjewar, PhD

Research Programs Manager | Hydrocephalus Association

Emily Meyers, PhD

Sr. Associate Director, Research Projects | Alzheimer's Association

2:00pm-3:00pm ET

Break

3:00pm-4:00pm ET
[Register here](#)

Sustaining The Research Pipeline: Supporting Early Career Investigators in a Changing Funding Landscape

This 60-minute session will feature lightning talks followed by an interactive panel discussion focused on sustaining the research pipeline by strengthening support for early- and mid-career investigators. Speakers will address the impact of recent federal policy changes on junior awardees, highlight effective support strategies in the current funding climate, and explore ways to build clearer pathways to additional funding mechanisms. The panel will actively engage attendees in identifying actionable approaches that funders, institutions, and organizations can adopt to mitigate challenges and support the next generation of researchers.

Moderator

Kylie McPherson, PhD

Associate Director of Research | Misophonia Research Fund

Speakers

Megan Allen, PhD

Scientific Director | Damon Runyon Cancer Research

Tammy Collins, PhD

Program Officer | Burroughs Wellcome Fund

Beryl Leach, MPH

Manager for Scientific Programs | Foundation of Physical Therapy Research

Clare Thibodeaux, PhD

Vice President of Scientific Affairs | Cures Within Reach

(agenda continues on next page)

12:00pm-1:00pm ET

[Register here](#)

Science Communication in the Current Information Ecosystem: Navigating Misinformation, Media, and Public Understanding

This session will explore the challenges and opportunities scientists, research administrators, and funders face in navigating misinformation within today's information ecosystem. With a focus on rare disease research, the discussion will examine issues around data accuracy, interpretation, and the ways complex scientific findings can be misunderstood or misrepresented. Panelists will also explore the evolving relationship between research producers and science communicators—including journalists, and media professionals—and highlight evidence-based strategies for effectively communicating research to non-expert audiences. By examining different sources of misinformation and successful approaches to countering them, this session aims to identify ways to build public trust and support informed decision-making.

Moderator

Kevin Sia, PhD

Program Officer for Medical Research | Doris Duke Foundation

Speakers

Renée DiResta

Social Media Researcher, Author - *Invisible Rulers: The People Who Turn Lies into Reality*

Leetha Filderman, FRSA

President/CEO | PopTech Institute

Alycia Halladay, PhD

Chief Science Officer | Autism Science Foundation