

# HEALTH RESEARCH ALLIANCE MEMBERS MEETING

October 16-17, 2023

**Hosted by the Alzheimer's Association**



The meeting will be held at Pendry Chicago Hotel (230 North Michigan Avenue Chicago, IL 60601) in the **Grand Ballroom or Gallery Ballroom (Floor 2 of The Pendry)**.

All sessions will be live streamed via Zoom unless otherwise noted

## October 16 | Monday

- 8:00 - 9:00am CT**      **Breakfast and Networking** (Including first time attendee meet and greet)
- 9:00am -10:45am CT**      **Managing Conflict and Challenging Conversations at Work**  
As part of HRA's Professional Development Program we are offering this pre-meeting workshop for staff of HRA members. The work environment is filled with conflict, often as a result of differences in work and communication styles. Minimizing or resolving conflict often requires engaging in difficult conversations, which is challenging and requires both practice and competency. This workshop will help attendees learn how to understand their own approach to work and will provide a framework for engaging in challenging conversations.
- For HRA Members only**
- This session will not be live streamed.*
- Garth A. Fowler, PhD**  
Associate Director for Systems, Process, and Analytics | Human Resources, Northwestern University
- 10:45am -11:00am CT**      **Break**
- 11:00am -12:00pm CT**      **Research Workforce and Early Career Development Learning Community**  
This session will showcase resources that support Early Career researchers in areas such as mental health, leadership and management, financial planning, and dependent care. These areas have been highlighted recently as being critical to recruitment, retention and well-being during the early career stage. Funders and universities have a vested interest in supporting their grantees to promote both recruitment and retention through the various stages of the academic pipeline. In this session, attendees are encouraged to share resources they have used within their organizations to support their grantees. We'll also be soliciting topics that the Research Workforce and Early Career Development Community can pursue beyond the HRA Fall Member's Meeting.
- Registry and Biorepository Learning Community**  
During this session, the Registry and Biorepository Community will be encouraging HRA members to share their questions, challenges, and experiences on topics suggested by members both before the meeting and during the session. Come prepared to ask questions and share lessons learned with your colleagues.
- 12:00pm -1:00pm CT**      **Networking Lunch**
- 1:00pm -1:30pm CT**      **Welcome to the Alzheimer's Association**  
**Maria Carillo, PhD**  
Chief Science Officer | Alzheimer's Association
- Welcome to the Members Meeting**  
**Maryrose Franko, PhD**  
Executive Director | Health Research Alliance

1:30pm - 2:45pm CT

**New Opportunities to Bridge the Research to Practice Gap**

How can funders move more of their funded research towards clinical relevance? This session will explore specific things philanthropic funders can do to increase the likelihood of improving patient outcomes. It will include a contextual update on how the research, regulatory, and commercial landscapes are changing, and how this might shift the highest impact funding opportunities for foundations. It will focus on how funders can help drive research findings into clinical practice, including strategies to empower stakeholders throughout the pipeline to work across cultural and professional boundaries.

**Moderator**

**Michelle McLeod, PhD, ATC** (virtual)

Director, Osteoarthritis Clinical Research Programs | Arthritis Foundation

**Facilitator**

**Lara Bethke, PhD**

Chief Science Officer | Health Resources in Action

**Presenters**

**Chris Austin, MD** (virtual)

Chief Executive Officer | Vesalius Therapeutics

**Peter Marks, MD, PhD** (virtual)

Director, Center for Biologic Evaluation and Research | U.S. FDA

**Harold Feldman, MD, MSCE** (virtual)

Deputy Executive Director | PCORI

2:45pm - 4:00pm CT

**Program Evaluation Learning Community: Using HRA Analyzer**

Bring your laptop and join the program evaluation community for a hands-on walk through of HRA Analyzer. Learn how to leverage this members-only resource and improve your research portfolio evaluation efforts. Diane Saunders will start by providing a brief walkthrough of HRA Analyzer, including sharing a few use case examples. Then we will have an interactive session to provide real-time support for participants to navigate the tool and begin interrogating data to addresses your organization's needs. This will give you the opportunity to troubleshoot and get guidance through queries and data export so that you leave the session with a clear idea of how to leverage this members-only resource to advance your organization's mission.

**Presenter**

**Diane Saunders, PhD**

HRA Analyzer Liaison | Health Research Alliance

4:00pm - 4:15pm CT

**Break**

4:15pm - 5:30pm CT

**Collecting and Leveraging Real-World Data**

The FDA defines real-world data (RWD) as that which relates to patient health status and/or the delivery of healthcare, often collected from a variety of sources, including the electronic health record (EHR), medical claims, disease registry data, direct input from patients, and digital health technologies. The use of this data and resulting evidence is vital to improving the efficiency of clinical research and bridging the gap between research and practice. This session will explore the usage of RWD for economics and health research, drug repurposing, and addressing unmet needs.

**Moderator**

**Elise Hoover, MPH**

Vice President of Research Programs | PKD Foundation

**Presenters**

**Christopher Boone, PhD**

Vice President, Global Head of Health Economics and Outcomes Research (HEOR) | AbbVie

**Smith (Smitty) Heavner, PhD**

Senior Scientific Director | CURE Drug Repurposing Collaboratory | Critical Path Institute

**Angela Dobes, MPH**

SVP, IBD Plexus | Crohn's and Colitis Foundation

**6:30pm - 9:30pm CT**    **Reception - (includes heavy hors d'oeuvres)**  
House of Blues (329 N Dearborn St, Chicago, IL 60654)

**October 17 | Tuesday**

**8:00am - 9:00am CT**    **Breakfast**  
Peer Circles will be meeting up during this time.

**9:00am - 10:00am CT**    **How to move from strategic planning through exploration to implementation and new program development**

When a funding organization has a strategic plan, that plan is expressed through the execution of its funding program(s). When an organization develops new strategic directions or objectives, then it is often necessary to design and implement new funding programs to pursue them. This session aims to examine and discuss real-world examples of this, including how programs were designed to fit the new purpose, how they were implemented and how their success was measured.

**Moderator**

**Kevin Sia, PhD**

Program Officer for Medical Research | Doris Duke Foundation

**Presenters**

**Shawna Strickland, PhD**

Associate Executive Director, Programs | American Epilepsy Society

**Patricia Frustace**

Senior Director of Awards and Diversity | American Society of Hematology

**Stephanie Albin, PhD**

Science Program Officer | The Kavli Foundation

**Jeremy Farrar, PhD** (*virtual*)

Chief Scientist | World Health Organization

**10:00am - 10:15am CT**    **Break**

**10:15am - 11:20am CT**    **How funders can work with universities to support early career scientists**

Being an early career researcher poses numerous challenges. These individuals require substantial support to nurture their innovative ideas and progress to the next phase of their professional journey. Both nonprofit funders and universities have a vested interest in supporting their scientists to develop their innovative ideas and move to the next stage of their career. In this session, speakers will discuss examples of ways in which funders and universities can work together to support early career scientists.

**Moderator**

**Megan Allen, PhD**

Scientific Director | Damon Runyon Cancer Research Foundation

**Presenters**

**Amanda Moualeu, MPH**

Senior Research & Grants Administrator | American Heart Association

**Patrick Brandt, PhD**

Director of Career Development and Outreach | Office of Graduate Education  
University of North Carolina at Chapel Hill

**Kim Lezak, PhD**

Managing Director of Biomedical Research Grantmaking | Health Resources in Action

11:20am - 12:45pm CT

*This session will not be live streamed*

Space for a networking lunch will be available.

### Misconduct and Ethics Learning Community over Lunch

This session will be a working group session focused on drafting language templates that funders can use across different communication methods throughout the course of a grant cycle. These include examples of misconduct and ethics policies, grant terms and conditions (T&Cs), event policies, and general communications to grantees. We will look at existing funder language and policies from the NIH, NSF, and UKRI for guidance.

As we discuss template language, we will ask participants to consider what important concepts are to convey to grantees, what language may need review by a legal team, and more.

12:45pm - 1:45pm CT

### Approaches to track and highlight the successes of our grantees

This session will discuss the use of alternative measures to track success in evaluating and highlighting the impact of grant funding – both during the grant term and post award. During this session we will learn strategies for collecting data from grantees and alumni to tracking research progress, and professional transitions (especially moving institutions or sectors). HRA member organizations will share measures (with a focus on “alternative metrics”) they use to track success and how they collect that data. Examples include patents/IP, follow on funding, career growth, publications (Altmetrics), research networks/collaborations, and/or policy or guidelines.

#### Moderator

**Jennifer Chang, PhD**

Science Manager | American Brain Tumor Association

#### Presenters

**Bruce Weinberg, PhD**

Eric Byron Fix-Monda Endowed Professor | The Ohio State University Department of Economics

**Lara Bethke, PhD**

Chief Science Officer | Health Resources in Action

1:45pm - 2:00pm CT

### Break

2:00pm - 3:15pm CT

### How the research landscape is changing

This session will discuss how biomedical research funding trends and priorities have evolved and continue to adapt. This session will discuss how the rising costs of research impacts what funders are doing, how funders have changed who they are funding in terms of career stage, and how funders have changed what types of science they are funding. To give a broad perspective, this session will include the perspective of philanthropic organizations and venture capitalism.

#### Moderator

**Kevin Sia, PhD**

Program Officer for Medical Research | Doris Duke Foundation

#### Presenters

**Cara Altimus, PhD**

Senior Director | Milken Institute Center for Strategic Philanthropy

**Lou DeGennaro, PhD**

Past President & CEO | The Leukemia & Lymphoma Society

**Jamie Kasuboski, PhD**

Vice President | OMX Ventures

3:15pm - 4:30pm CT

### AI and Large Language Models Learning Community

Attendees to the AI and LLMs Learning Community session will discuss the impact of newly established policy topics around AI and LLM (e.g. what is needed in policies to address using AI effectively, fairly, safely, in grantmaking and patient engagement to advance our missions), and resources (the [NIH policy](#), the [JAMA study](#), etc) on the research environment. The session will also discuss additional topics of interest suggested by HRA members - either before or during the session and in this [google doc](#).