

HEALTH RESEARCH ALLIANCE MEMBERS' MEETING

March 12-13, 2018



Sponsored by the Simons Foundation

All sessions will be held at the Simons Foundation (1605th Ave, New York)

March 12 | Monday

8:00- 9:00 AM **Breakfast and Networking**

9:00- 10:00 AM **Pre-Meeting Session**

(60min)

ORCID Reducing Burden and Improving Transparency (ORBIT) Project

This presentation will introduce strategy to reduce investigator burden and improve funder efficiency through the use of persistent identifiers. The NIH is currently engaged in pilot efforts with ORCID and Crossref (two non-profit groups) and other non-governmental funders to better manage funding and investigator data. The presentation will introduce the ORBIT project, a partnership between the NIH and ORCID that expands the ORCID data model to collect faculty profile information. The presenters will describe efforts to assign Digital Object Identifiers (DOIs) to grants - effectively creating a universal funding identifier with ORCID IDs in its metadata.

ORCID assigns unique persistent identifiers to researchers. These enable automated linkages between researchers and their professional activities making this info easily discoverable and simplifying reporting and analysis. Crossref assigns unique persistent identifiers to research objects, to make them easy to find, cite, link and assess. Thousands of journals use ORCID and DOIs as part of their workflow, and with the user's permission, can automatically populate ORCID user accounts with citations when they publish.

Presenters

Neil Thakur, PhD

Special Assistant to NIH Deputy Director for Extramural Research | NIH

Geoffrey Bilder

Director of Strategic Initiatives | Crossref

Laurel Haak, PhD

Executive Director | ORCID

10:00- 10:30 AM **Break**
(30min)

10:30- 11:00 AM **Welcome to the Members' Meeting and Introductions**

(30min)

HRA Board Chair

Steve Rose, PhD

Chief Science Officer | Foundation Fighting Blindness

Program Committee Co-Chairs

Sindy Escobar-Alvarez, PhD

Senior Program Officer for Medical Research | Doris Duke Charitable Foundation

Nicole Willmarth, PhD

Chief Science Officer | American Brain Tumor Association

Simons Foundation

Marion Greenup, MPH, MEd

Vice President for Administration | Simons Foundation

11:00AM- 12:30PM **Health Services Research**
(90min)

Health Services Research (HSR) is a multidisciplinary field of research, both basic and applied, that examines multiple factors affecting research outcomes directly affecting the target population, including costs, quality, accessibility, delivery, organization, and financing to maximize benefit for individuals and populations. The goal of this session is to provide an overview of the discipline of HSR and relevant research questions, to offer examples of how it is integrated into health sciences funding programs, and to provide practical considerations funders should consider when incorporating the priorities of HSR into their RFAs and reporting requirements.

Moderator

Lynne Garner, PhD

President CEO | Donaghue Foundation

Presenters

Lisa Simpson, MB, BCh, MPH, FAAP

President and CEO | AcademyHealth

Lori Melichar, PhD

Director, Pioneer Portfolio | Robert Wood Johnson Foundation

Susan Fitzpatrick, PhD

President | James S. McDonnell Foundation

12:30- 2:00PM
(90min)

Breakout Sessions Over Lunch

- Health Services Research
- FIRST

2:00 - 3:00PM
(60min)

Host/Science Session

John Spiro (Deputy Scientific Director, Simons Foundation Autism Research Initiative (SFARI)) will give a brief overview of SFARI's history, programs, and resources—and then will focus on a history of our understanding of autism genetics and biology through the lens of 3 different cohorts that are funded and managed by SFARI: The Simons Simplex Collection (SSC), The Simons Variation in Individuals Project (Simons VIP), and Simons Foundation Powering Autism Research for Knowledge (SPARK). Pam Feliciano (Scientific Director, SPARK) will talk about some recent challenges in recruiting and engaging tens of thousands of SPARK participants, including returning genetic results.

Moderator

John Spiro, PhD

Deputy Scientific Director | Simons Foundation

Welcome and Introduction to the Simons Foundation

Marilyn H. Simons, PhD

President | Simons Foundation

Presenters

John Spiro, PhD

Deputy Scientific Director | Simons Foundation

Pam Feliciano, PhD

Scientific Director of SPARK | Simons Foundation

3:00 - 3:30 PM
(30min)

Break

March 12 | Monday (continued)

3:30 - 4:45PM
(75min)

Breaking the Mold: New Models in Research Funding

Research funding mechanisms usually require a number of standard documents (i.e., research proposal, biographical sketches, and budget) and go through a peer review process. A number of groups however, are trying new approaches to accelerate innovation and solve tough problems through novel funding mechanisms. In this session, we will hear from three organizations using funding models ranging from endowments and venture philanthropy to unique scientific gatherings and ways to connect academic research to drug discovery and clinical studies. During this session, speakers will discuss the rationale for using their approaches, key considerations when developing and implementing a certain approach, and the successes and pitfalls of using such approaches.

Moderator

Shannon Gallagher-Colombo, PhD

Assistant Director, Scientific Review and Grants Administration | AACR Foundation

Presenters

Simon Noble, PhD

Director, Science Communication | CHDI Foundation

Member Presenters

➤ **Christopher Martin, PhD**

Interim Vice President of Science Programs | The Kavli Foundation

➤ **Michael Batten, MD, MBA**

Director, JDRF T1D Fund | JDRF

6:00 - 8:00 PM

Group Reception (includes heavy hors d'oeuvres.)

Location: 2nd floor event space of the Redbury New York Hotel (29 E 29th St, New York, NY 10016)

March 13 | Tuesday

8:00 - 9:00 AM
(60min)

Breakout Sessions Over Breakfast

- Grants Program Analysis
- Drug and Other Therapy Development

9:00 - 10:30 AM
(90min)

Implementation of Funder Data Sharing Policies

In this session, HRA members will share their process, considerations, and implementation of data sharing policies. These funders will share how their policies were conceived, whether input from the scientific community and other stakeholders was sought and used to craft the policies, how the policies are being implemented, and suggested best practices learned along the way. Our guest speaker will provide his perspective as a clinical researcher and proponent for open data access regarding the need to transform the scientific enterprise and the key role of funders in that effort. He will talk about practical considerations and discuss a model to make data available in a sustainable way so that data sharing becomes a vital part of the clinical research enterprise of the future.

Moderator

Amy Laster, PhD

Senior Director, Grants and Awards Programs | Foundation Fighting Blindness

Presenter

Harlan Krumholz, MD, SM

Harold H. Hines Jr. Professor of Medicine | Yale School of Medicine

Member Presenters

➤ **Jason Gerson, PhD**

Senior Program Officer | PCORI

➤ **Belinda Orland, MBA**

Senior Manager, Research Operations | American Heart Association

10:30 - 11:00 AM Break
(30min)

11:00AM- 12:30PM Strategies for Increasing Diversity in the Workforce
(90min)

This session will focus on the challenges and opportunities of diversity and unconscious bias that women and minorities face in peer review in academic science. To set the stage for this session, HRA members will participate in an exercise to demonstrate implicit bias. We will hear about an evidence-based approach to understand the basis of this problem, along with a pilot scheme that US institutions are undertaking to assess inequality, identify problem areas, and set plans to reduce disparities. Finally, we will hear from an HRA member organization that has implemented strategies to promote gender equity in funding for a career development award. A follow-up breakout session will give HRA members a chance to review their own processes and refine them based on the learnings discussed in this session.

Moderator

Kristen Mueller, PhD

Scientific Program Director | Melanoma Research Alliance

Presenters

Anna Kaatz, PhD

Director of Computational Sciences | University of Wisconsin

Shirley Malcom, PhD

Director of Education and Human Advancement | AAAS

Member Presenter

➤ **Sindy Escobar Alvarez, PhD**

Senior Program Officer for Medical Research | Doris Duke Charitable Foundation

12:30 -2:00 PM
(90min)

Breakout Sessions Over Lunch

- Research Workforce and Early Career Development
- Grants Administration

2:00 - 2:30 PM
(30min)

HRA News and Updates

Maryrose Franko, PhD

Executive Director | Health Research Alliance

- [HRA Open](#) Launch
- HRA Reporter going public (in aggregate)
- HRA – ORCID Consortium
- Funder-University Workshop, May 16

2:30 - 2:45 PM
(15min)

Wrap- up and Adjourn