

HEALTH RESEARCH ALLIANCE MEMBERS MEETING

September 25-26, 2019



Sponsored by Conquer Cancer and the BrightFocus Foundation
Reception sponsored by the Donaghue Foundation and Melanoma Research Alliance

All sessions will be held at the ASCO Conference Center in Alexandria, VA

September 25 | Wednesday

10:00 – 10:30 AM

(30 min)

Welcome to the Members Meeting

HRA Board Chair

Stephen Rose, PhD

Chief Science Officer | Foundation Fighting Blindness

HRA Executive Director

Maryrose Franko, PhD

Executive Director | Health Research Alliance

Program Committee Co-Chairs

Caren Heller, MD, MBA

Chief Scientific Officer | Crohn's & Colitis Foundation

Chris Martin, PhD

Senior Science Program Officer & Director, Science Operations | The Kavli Foundation

Welcome

Nancy R. Daly, MS, MPH

Executive Vice President & Chief Philanthropic Officer | Conquer Cancer

10:30 – 12:00 PM

(90 min)

Effective Approaches to Increase Diversity and Inclusion in the Biomedical Research Workforce

The research workforce does not reflect the diversity of the U.S. population and individuals from specific groups remain underrepresented in the biomedical research workforce. According to the National Science Foundation, 8% of U.S. residing doctoral scientists and engineers are African American or Black, American Indian, Alaska Natives, or Hispanic Latinos. The number of individuals from these groups would have to quadruple to reach parity with the demographics of the US population. Funders and research institutions alike have engaged in efforts to expand the talent pool by increasing diversity in the workforce. This session will present different approaches that funders have taken to address this issue, the limitations of their approaches, and address the question of what works and what doesn't work. A diversity officer from a research-intense institution will offer advice on other ways in which funders can support effective diversity and inclusion efforts.

Moderator

Katrina Bandong, MS

Program Associate for Medical Research | Doris Duke Charitable Foundation

Presenters

Lisa Evans, JD

Scientific Workforce Diversity Officer | NIH

Kumea Shorter-Gooden, PhD

Principal/Owner | Shorter-Gooden Consulting

Member Speakers

Krissa Smith, PhD

Director, Research Programs | Susan G. Komen

Patricia Frustace

Director of Awards and Diversity | American Society for Hematology

12:00 – 1:15 PM
(75 min)

LUNCH: BREAKOUTS & NETWORKING

Main Meeting Room:

- [Grants Administration](#)
- [Open Science Task Force](#)

Founders board room

- Networking

1:15 – 2:15 PM
(60 min)

Translating the Microbiome: Past, Present, and Future

Research over the last decade has revealed the enormous diversity of the human microbiome and the myriad of ways that it impacts health and disease. Dr. Lita Proctor, PhD, the former Coordinator of the Human Microbiome Project (HMP), will present some of the findings of the HMP, and its second phase, the integrative HMP, as well as discuss how the scientific community is moving past inventorying and into establishing cause and effect. She will also discuss where microbiome research should head in the future – for instance, can microbiome research be translated to improve health and treat disease?

Moderator

Margaret Flowers, PhD

Director, Scientific Communications and Grants | Breast Cancer Research Foundation

Presenter

Lita Proctor, PhD

Former Program Director | Human Microbiome Project, NIH/NHGRI

2:15 – 3:15 PM
(60 min)

Highlighting our Sponsors

3:15 – 3:35 PM
(20 min)

Break

3:35 – 4:30 PM
(55 min)

BREAKOUT & NETWORKING

Main Meeting Room:

- [FIRST Group](#)

Founders board room

- Networking

4:30 – 5:45 PM
(75 min)

Open Mic: Exciting and Innovative Activities by HRA Members

During this session, we will get together to learn from the experiences of fellow HRA members. HRA members will present innovative and exciting activities of their organizations to tackle some of the toughest challenges we face as research funders. The attendees are encouraged to participate in the session and share the exciting and innovative ideas their organization has tried to address, an identified challenge area that would be beneficial for the group to learn about.

MC's

Caren Heller, MD, MBA

Chief Scientific Officer | Crohn's & Colitis Foundation

Chris Martin, PhD

Senior Science Program Officer & Director, Science Operations | The Kavli Foundation

6:30 – 8:30 PM

Reception with Heavy Hors D'Oeuvres at the Carlyle Club
(2050 Ballenger Avenue)

8:15 – 9:30 AM
(75 min)

BREAKFAST: BREAKOUTS & NETWORKING

Main Meeting Room:

- [Expanding Your Impact Beyond The U.S. Borders: Acting Locally, Thinking Globally](#)
- [Drug and Other Therapy Development](#)

Founders board room

- Networking

9:30 – 11:00 AM
(90 min)

Creating Networking and Partnering Opportunities

Strategic partnering is becoming an increasingly valuable approach for nonprofits to advance their missions. This session will present three different types of strategic partnerships: partnering with FDA to accelerate approval of new therapies for rare diseases; advocacy partnering to increase support for a mission-related NIH center; and pharmaceutical partnering related to a foundation-developed patient registry. Representatives from the partnering organizations will present why and how they partner to create win-win outcomes, and they will be joined by their partnering HRA members on a panel to address audience questions.

Moderator

Kristen Mueller, PhD

Scientific Program Director | Melanoma Research Alliance

Presenters

Andrea Furia-Helms, MPH

Acting Director, Patient Affairs Staff, Office of Medical Products and Tobacco, | Food and Drug Administration (FDA)

Debbie Drell *(invited)*

Director of Membership | National Organization for Rare Disorders (NORD)

James Jorkasky

Executive Director | National Alliance for Eye and Vision Research (NAEVR)

Steven Brunette, PhD

Senior Associate Director, Patient Affairs and Engagement | Boehringer-Ingelheim

Member Speakers

Neil Thakur, PhD

Executive Vice President, Mission Strategy | The ALS Association

Ben Shaberman

Senior Director, Scientific Outreach & Comm Engagement | Foundation Fighting Blindness

Angela Dobes, MPH

Senior Director, IBD Plexus | Crohn's & Colitis Foundation

11:00 – 11:15 AM
(15 min)

Break

11:15 AM – 12:15 PM
(60 min)

The Role of the Funder in Providing Mentoring Experiences for Grantees

During this session, we will explore how funders can provide support for mentoring within their programs as a part of workforce development. We will review a summary of current mentoring practices by HRA members. This will be followed by a talk from Dr. Chris Pfund from the University of Wisconsin-Madison. Dr. Pfund will discuss the national landscape of mentoring in STEM and provide resources that funders can use to support grantees. This main session will be followed by a breakout session where Dr. Pfund will lead HRA member organizations through the development of an implementation plan where they identify resources that best fit with their program needs and structure.

Moderator

Kara Coleman, PhD

Project Director, Biomedical Programs | The Pew Charitable Trusts

Presenter

Christine Pfund, PhD

Associate Scientist | Univ. Wisconsin-Madison

Director | Center for the Improvement of Mentored Experiences in Research, Wisconsin Center for Education Research

12:15 – 1:45 PM
(90 min)

LUNCH: BREAKOUTS & NETWORKING

Main Meeting Room:

- [Research Workforce and Early Career Scientists](#)
- [Patient Registries](#)

Founders board room

- Networking

1:45 – 3:00 PM
(75 min)

Fact vs. Fiction

Public opinion shapes attitudes about science, research funding, and health policy. In a crowded media environment where objectivity and trust cannot be presumed, how can funders and scientists leverage media to improve public health? This panel features two experts working at the intersection of science and communication. Sarah Gollust, PhD, Associate Professor, Division of Health Policy and Management at the University of Minnesota, examines “processes through which health information gets translated into the media, shapes public attitudes and opinions, and influences the health policy process.” Laura Helmuth, PhD, is the Health, Science and Environment Editor at The Washington Post and has covered health and medical research for more than 20 years. She also has a doctorate degree in cognitive neuroscience.

Moderator

Joe Cotter

Research Constituent Engagement Manager | American Cancer Society

Presenters

Sarah Gollust, PhD

Associate Professor, School of Public Health | Univ. of Minnesota

Laura Helmuth, PhD

Health, Science and Environment Editor | The Washington Post

3:00 PM

Adjourn