

# 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**