

# HEALTH RESEARCH ALLIANCE MEMBERS' MEETING

March 23-24, 2017



## Co-Sponsored by

- Pancreatic Cancer Action Network
- Kavli Foundation
- W.M. Keck Foundation
- Kenneth Rainin Foundation
- Arthritis National Research Foundation

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All main sessions will be held in the **Manhattan A Ballroom** of the Manhattan Beach Marriott

## March 23 | Thursday

### 11:00AM- 12:00 PM **Altmetrics (Optional Session)** (60min)

It's been over five years since the term "alt-metrics" was coined and the metrics landscape has radically altered in that time. Research producers and funders, from large academic institutions to global funders to small nonprofits and institutes, are using these new metrics in ways not thought of even two years ago.

We've found organizations are continuously discovering new and innovative ways to use Altmetric data for everything from competitive intelligence to tech transfer to finding new clinical trials communities to evaluating grant applications.

This session will review key use cases we've seen in the last year across all the major sectors we support: academic, corporate, government, funder, and nonprofits - with emphasis on how nonprofits and foundations are using altmetric data - including HRA Members.

In this session, we will cover:

- What are altmetrics.
- How altmetrics are being used by foundations and nonprofits today, including examples from foundations/nonprofits like the John Templeton Foundation.

#### **Presenters**

##### **Monika Dunbar**

Director, Nonprofits and Foundations | ÜberResearch and Digital Science

##### **Sara Rouhi**

Director, North America | Altmetric

### 12:00 – 1:00 PM **Registration and Lunch** (60min)

**1:00 - 1:15PM  
(15min)**

**Welcome to the Members' Meeting and Introductions**

**Program Committee Co-Chairs**

**Mary DeRome**

Director Medical Communication and Education | Multiple Myeloma Research Foundation

**Diana Shineman, PhD**

Senior Director, Scientific Affairs | Alzheimer's Drug Discovery Foundation

**HRA Board Chair**

**Betsy Myers, PhD**

Program Director for Medical Research | Doris Duke Charitable Foundation

**1:15 - 2:30PM  
(75min)**

**Successful Implementation of Open Science and Data Sharing**

The use of online platforms for researchers to openly share data with their colleagues, as well as the public, is a concept that is gaining growing interest among the scientific community. While important strides have been made in encouraging the use of data-sharing platforms in the interest of advancing scientific discovery and research reproducibility, there remain barriers to universal adoption and acceptance of such platforms. For example, the practical concerns of the researcher about whether openly-shared data will put them at a competitive disadvantage, or be potentially misused or misinterpreted. Further complicating the adoption of data-sharing is the lack of knowledge about which platforms one should use to share data, what data should be shared on the platform, and the value of contributing to such a platform. In this session, we will learn what we as funders can do to encourage and educate our scientists about the utility of data-sharing, as well as educate ourselves on best practices for data-sharing. The key note speaker will discuss the function of several data sharing platforms, and provide insights on the advantages and disadvantages of different platforms. Several HRA members will share their experiences in encouraging, and even mandating, the use of data-sharing by their grantees. A panel discussion will follow, with the goal of encouraging an open dialogue among attendees about how funders can encourage and support open science by facilitating data sharing by their grantees. Topics of discussion will include whether members encourage or require data-sharing by their grantees, what is the typical period of exclusivity for the data, what the response from grantees has been, and how funding organizations have addressed these challenges.

**Moderator**

**Shannon Gallagher-Colombo, PhD**

Assistant Director | AACR Foundation

**Presenter**

**Robert L. Grossman, PhD**

Chief Research Informatics Officer | Biological Sciences Division | University of Chicago

**Member Speakers**

➤ **Salvatore La Rosa, PhD**

VP Research and Development | Children's Tumor Foundation

➤ **Justin Guinney, PhD**

Director, Computational Oncology | Sage Bionetworks

**2:30 - 3:00 PM  
(30min)**

**Break**

**3:00 - 4:15 PM  
(75min)**

**Demystifying Indirect Cost in Funder Agreements**

As you work on your grant agreements and contracts, do you ever wonder what those “indirect costs” or “F & A costs” are and what should be included? There is no universal rule for classifying certain costs as either direct or indirect (F&A) under every accounting system. A cost may be direct with respect to some specific service or function, but indirect with respect to a government award or other final cost objective. There is a growing gap between funding organizations and academic institutions regarding classification of indirect costs in non-governmental sponsored projects. As HRA explores defining indirect costs, this session will focus on understanding the current challenges funding organizations and academic institutions face regarding indirect cost definitions and rates. The session will also discuss different strategies used by HRA members and academic institutions to resolve problems associated with indirect costs. This session will include a moderated panel discussion of experts from both sides of the issue and aims to manage expectations and develop strategies to foster productive conversations toward solutions that will be acceptable to all stakeholders.

**Moderator and Presenter**

**Anita Pepper, PhD**

VP of Development | Wistar Institute

**Presenter**

**Sally O’Neil**

Director, Industrial Contract Office | Stanford University

**Member Speaker**

➤ **William Chambers, PhD**

Senior Vice President, Extramural Research | American Cancer Society

➤ **Louise Perkins, PhD**

Chief Science Officer | Melanoma Research Alliance

➤ **Chris Percopo, MPA**

Director of Grants Management | Helmsley Charitable Foundation

**4:15 - 5:15 PM  
(60min)**

**Highlighting our Sponsors**

**Moderator**

**Betsy Myers, PhD**

Program Director for Medical Research | Doris Duke Charitable Foundation

**Presenters**

**Helene Belisle**

Executive Director and Secretary | Arthritis National Research Foundation

**Miyoung Chun, PhD**

Executive Vice President of Science Programs | Kavli Foundation

**Jackie Hausman**

Program Officer, Health | Kenneth Rainin Foundation

**Julie Fleshman, JD, MBA**

President and CEO | Pancreatic Cancer Action Network

**Maria Pellegrini, PhD**

Executive Director of Programs | W.M. Keck Foundation

**6:00 – ?**

**Group Reception and Dinner at Shade Redondo Beach**

*(shuttles will be provided)*

7:45 - 9:00 AM  
(75min)

**BREAKFAST**

**NETWORKING**

**ROOM: MAIN MEETING SPACE (MANHATTAN A)**

**RESEARCH WORKFORCE AND  
EARLY CAREER DEVELOPMENT WORKING GROUP**

**ROOM: TERRACE B**

This roundtable discussion will be divided into three sections. First, members will receive a summary of the strategic plan developed from discussion at the last members' meeting. Interested individuals will be encouraged to volunteer for one of several "task forces" to help create shared resources focused on workforce development for all HRA members. Next, we will discuss best practices and brainstorm new ways on how to track alumni and keep grantees engaged.

Last, we will have a special talk on a network of programs supported under the NIH BEST (Broadening Experience in Scientific Training) initiative, which provides graduate students/trainees opportunities to learn about career paths in the non-profit funder sector (or just learn about what non-profit funders do) via an internship with host foundations. There may be opportunities for HRA member organizations to participate in the initiative.

**GRANTS ADMINISTRATION INTEREST GROUP**

**ROOM: TERRACE A**

Including Patients/Advocates in Peer Review

We will discuss the use of non-scientists in the peer review process. Please come prepared to discuss your organization's experiences. The pros, cons, and benefits of including patients and/or advocates to gain input from their unique perspective. If your organization utilizes this practice for peer review, how much of the committee is represented by this constituency? Do you conduct any training? Please come prepared to discuss.

If there is enough interest, we will break into groups and also discuss the following:

- Patient advisors for foundation strategic planning – how they would like us to spend our money, best bang for the buck, areas of concentration important to patients
- Patient advisors for foundation programming – act as guides for patient education and outreach efforts, modes of communication, topics, etc.
- Patient advisors for pharma partners – provide feedback on drug regimens, side effects, route of administration, patient hardships while on therapy, things patients would change in these areas if they could (length of time for infusions, how many pills how often, etc)
- How best to bring patients together (physically or otherwise) to act as advisors, in a way that is most convenient and offers the least disruption of their daily lives

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

**Addressing Inefficiencies to Accelerate Future Clinical Trials**

Presenters will share information about their role and strategies to accelerate clinical trials. Individual panel members will discuss their approaches in precision medicine and in the identification, validation and regulatory acceptance of clinical trial endpoints. Internal resources, partnerships, funding mechanisms used, and challenges will be presented to inform funders considering ways in which they can contribute to the acceleration of therapies for their disease areas of interest.

**Moderator**

**Sindy Escobar Alvarez, PhD**

Senior Program Officer for Medical Research | Doris Duke Charitable Foundation

**Presenter**

**Stephen Joel Coons, PhD**

Executive Director | Patient-Reported Outcome Consortium Critical Path Institute

**Member Speakers**

➤ **Julie Fleshman, JD, MBBA**

President and CEO | Pancreatic Cancer Action Network

➤ **Mary DeRome**

Director Medical Communication and Education | Multiple Myeloma Research Foundation

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

11:00AM- 12:15 PM **Convergence: Platform Technologies to Accelerate Life Science Discovery**  
(75min)

From <http://www.convergencerevolution.net/> : “Convergence is the integration of engineering, physical sciences, computation, and life sciences—with profound benefits for medicine and health, energy, and environment.” In this session, speakers actively practicing convergence from the perspectives of philanthropy, government, physical science, and life science, will describe the lessons learned and insights for future approaches to accelerate discovery across the broad range of HRA member interests. Ideas for how to implement these approaches will be summarized and discussed so that HRA members in the audience can put them in place should they wish.

**Moderator**

**Chris Martin, PhD**

Science Program Officer | The Kavli Foundation

**Presenter**

**Marcia McNutt, PhD**

President | National Academy of Sciences

**Member Speakers**

➤ **Maria Pellegrini, PhD**

Executive Director of Programs | W.M. Keck Foundation

➤ **Jennifer Hall, PhD**

Chief, AHA Institute for Precision and Cardiovascular Medicine | American Heart Association

➤ **Chris Martin, PhD**

Science Program Officer | The Kavli Foundation

12:15 – 12:45 PM **Private Philanthropy and Biomedical Research: Fresh Perspectives from a New Generation of Donors**  
(30min)

Emerging philanthropists on the West Coast, many of whom are from the technology sector, have announced ambitious projects to support biomedical research in bold and innovative ways. Facebook founder Mark Zuckerberg and his wife Priscilla Chan have made a \$3 billion commitment over the next 10 years to "cure, prevent, or manage all diseases in our children's lifetime." As part of that commitment, \$600 million has been pledged to create the Chan Zuckerberg Initiative (CZI) Biohub, a collaborative network of scientists and engineers from Stanford, UC Berkeley, and UC San Francisco. Facebook co-founder Sean Parker has also pledged \$600 million to create a cancer immunotherapy institute as part of the Parker Foundation. In this session we will hear from Valerie Conn, Vice President of the Science Philanthropy Alliance, a community of funders with a mission to increase private funding for basic science research. How will these new initiatives accelerate, transform or even disrupt traditional models of biomedical funding? How do they set strategies and priorities for their funding in basic science? What are some opportunities for HRA member organizations or practices that HRA members can consider?

**Moderator**

**Kevin Lee, PhD**

Scientific Advisor | Glenn Foundation for Medical Research

**Presenter**

**Valerie Conn**

Vice President | Science Philanthropy Alliance

12:45 - 2:00 PM  
(75min) **LUNCH**

**NETWORKING**

**ROOM: TERRACE A**

**OPEN SCIENCE TASK FORCE**

**ROOM: TERRACE B**

This breakout session will build off of the conversation from the day 1 session: “Successful Implementation of Open Science and Data Sharing”. The breakout will be led by the co-chairs of the Open Science Task Force, and will provide an opportunity for HRA members to share their experiences in successfully implementing an open science policy. We hope this breakout will also be informative to HRA members who have an interest in implementing such policies, but have not yet been able to do so.

2:00 - 3:30 PM  
(90min)

**Putting Grants Data to Work: Practical Approaches to Evaluation**

At the heart of grantmaking is the desire to bring about positive change. For HRA members, it means maximizing the impact of biomedical research to improve human health. As funders, we are being increasingly tasked with evaluating our grant giving to understand if what we're doing works and especially what works well. In previous HRA meetings, we have heard different approaches funders have used to help answer these questions -- how they are assessing their grant programs to determine the return on their investments, to improve grantee performance, inform future grantmaking and demonstrate responsible stewardship to donors and the public. This session continues this effort and presents other options for our toolkit. Member speakers will share experiences evaluating their grants programs, how results are communicated with their different stakeholders and lessons learned. Presentations will address the use of different bibliometrics and “scientometrics” for measuring grantee performance and scholarly and scientific impacts or contributions of grants, and how these data are evaluated and visually presented to help tell a compelling story.

**Moderator**

**Jenna Koschnitzky, PhD**

Director of Research Programs | Hydrocephalus Association

**Presenter**

**Katie Hickling**

Product Manager | PLoS

**Member Speakers**

➤ **Micah Moughon**

Research Information Manager | American Heart Association

➤ **Kari Wojtanik, PhD**

Sr. Manager, Evaluation & Outcomes | Susan G. Komen

➤ **Rachel Witsamen MPH, PMP**

Program Officer | PCORI

3:30 - 4:15 PM  
(45min)

**HRA News and Updates – open to all attendees**

**Update on HRA’s Reporter and Infographic Update**

**Lorraine Egan, JD**

President and CEO | Damon Runyon Cancer Research Foundation

**Update on HRA’s Interest Groups and Task Forces**

**Sindy Escobar-Alvarez, PhD**

Senior Program Officer for Medical Research | Doris Duke Charitable Foundation

- ***Open Science Task Force***

**Maryrose Franko, PhD**

Executive Director | Health Research Alliance

- ***Research Workforce and Early Career Development***
- ***Grants Administration***
- ***Drug and Other Therapy Development***
- ***FIRST***
- ***New Frontiers in Science Distinguished Lectureship Program at the FDA***

**Implementation of the Strategic plan**

**Maryrose Franko, PhD**

Executive Director | Health Research Alliance

- ***Slack***
- ***Communications Advisory Group***
- ***Members’ Meeting Task Force***
- ***Annual Survey***

4:15 - 4:30 PM  
(15min)

**Program Committee Co-Chairs**

**Mary DeRome**

Director Medical Communication and Education | Multiple Myeloma Research Foundation

**Diana Shineman, PhD**

Senior Director, Scientific Affairs | Alzheimer’s Drug Discovery Foundation

**Executive Director**

**Maryrose Franko, PhD**