Optional Pre-Meeting Session:

**Program Evaluation: Leveraging Shared Award Data and Other Data Sources**

How are funding organizations using their own grant data and other data sources to inform their program planning and evaluation projects? More than ever, we have access to huge amounts of data. In addition to the award data in our grants management systems, we have award data from other funders (HRA RePorter, UberResearch Dimensions); publication data from PubMed and private data sources; patents from USPTO (Patents); and Altmetrics. How do we find the answers to our questions in all of this data? How do we show value for the cost and effort required to assemble and analyze it? How do we use this data to inform program decisions, patient advocates, donors, or our Board? The presenters offer a wide range of experience across funding organization and will provide examples from successful projects. The objective of these case studies is to provide some ideas you can use today and to encourage discussion about the opportunities, and challenges facing funders in analyzing big data.

**Presenters**

**Jamie McKee**  
Director, Business Development | Altum, Inc.

**Ashlee Higgs**  
Managing Director | UberResearch

Registration and Lunch

Welcome to the Members’ Meeting and Introductions

**HRA Board Chair**  
**Betsy Myers, PhD**  
Program Director for Medical Research | Doris Duke Charitable Foundation

**Program Committee Chair**  
**Nicole Willmarth, PhD**  
Chief Science Officer | American Brain Tumor Foundation

**Welcome and Introductions to the Alzheimer’s Association**

**Harry Johns**  
Chief Executive Officer | Alzheimer’s Association
### Strategic Planning

During this session, member organizations will hear expert facilitators of strategic planning provide in-depth perspective on the “how to” regarding framing the strategy and next steps for either organizational or programmatic planning. Following this overview, attendees will hear first-hand how these methods applied to a fellow HRA member organization and then have an opportunity to apply these components to create a mock strategic plan for a ghost program or organization during a facilitated workshop. After this session, attendees will understand the basic steps to creating a strategic plan and understand the pieces that are required to execute those steps for future implementation at their own organizations.

**Moderator**

Margaret Flowers, PhD  
Associate Director, Grants and Scientific Communications | Breast Cancer Research Foundation

**Presenters**

Melissa Stevens, MBA  
Executive Director, Center for Strategic Philanthropy | Milken Institute

Jackie Hausman, MPP, MPH  
Program Officer for Health | Kenneth Rainin Foundation

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### Break

2:45 - 3:00 PM  
(15min)

### INTEREST GROUP BREAKOUTS

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### Accelerating treatments to Patients – Crossing the “Valley of Death”

Going from an idea to a drug that can be tested in human patients is a long and arduous path. The later stages of preclinical development, including toxicology testing, drug manufacturing, and formulation are critical to gain approval from the FDA to move in human testing, but it is often quite challenging to secure funding for these types of studies. This stage of drug development is often referred to as the “valley of death” as many promising drug programs are not able to secure the necessary financing or partnerships to move forward. In addition, building an adequate intellectual property portfolio and commercialization plan is also critical in bringing a treatment to patients. What can we as foundations do bridge the “valley of death” and accelerate more treatments into human clinical testing and ultimately to patients in need? Foundations can’t do this alone so this session will include a panel of speakers illustrating cross-sector collaborations and innovative resources.

**Moderator**

Diane Bovenkamp, PhD  
Vice President, Scientific Affairs | BrightFocus Foundation

**Presenters**

Eric Schaeffer, PhD  
Science Director, Scientific Innovation, Neuroscience | Johnson and Johnson Innovation Center

Joel Braunstein, MD, MBA  
Co-Founder, President and CEO | C2N Diagnostics

**Member Speakers**

- Andrew Koemeter-Cox, PhD  
  Scientific Program Officer | Alzheimer’s Drug Discovery Foundation

- Melissa J. Nirenberg, MD, PhD, FAAN  
  Chief Medical Officer | The New York Stem Cell Foundation

- Robert Sege, MD, PhD  
  Chief Medical Officer & Director | The Medical Foundation at Health Resources in Action

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### 6:00 –8:00 PM

**Group Reception at Smith & Wollensky Grille Chicago**

318 N. State St., about an 8 minute walk from hotel
**September 18 | Monday**

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| 8:00 - 9:30 AM (90min) | **BREAKFAST**  
**NETWORKING & INTEREST GROUP BREAKOUTS** |
| 9:30 - 9:45 AM (15min) | **Presentation of initial analysis of the inaugural Annual Member Survey**  
Maryrose Franko, PhD  
Executive Director | Health Research Alliance |
| 9:45 - 10:45 AM (60min) | **Alzheimer’s disease biomarkers to accelerate clinical development and to improve clinical practice**  
Biomarkers provide invaluable information, not only for our understanding of the underlying processes of disease, but also in the context of clinical trials, and for use in clinical practice for diagnosis. The development of biomarkers (imaging and fluid) is revolutionizing our understanding of Alzheimer’s disease. In this session, Alzheimer’s disease biomarkers such as PET (positron emission tomography) and biomarkers in CSF (cerebrospinal fluid) will be discusses and how they are leading to more accurate diagnosis and to the development of better treatments.  
**Moderator**  
Maria Carrillo, PhD  
Chief Science Officer for Medical and Scientific Relations | Alzheimer’s Association |
| 10:45 - 11:45 AM (60min) | **Speak Visually: How to Use Visual Communication to Tell Your Research Story**  
Did you know that the average person only reads 20% of the content put in front of them if that content has more than 600 words? As research funders, this creates a huge hurdle to overcome. Now more than ever today’s audiences communicate in short, bite-sized conversations with visual media as their primary language. These visual conversations are happening all around us, and organizations are rushing to catch up so that they can speak visually in return. But in the rush to connect and share results, organizations often miss the mark leading to misunderstandings or worse: a lack of faith in the end product as a result of low-quality execution. So how can you communicate your research story in a way that connects with your target audience versus turning them off?  
Killer Infographics is an industry leading visual communications agency with a goal of helping clients speak visually through targeted campaigns that transform how organizations of all sizes connect with their audiences. For years, the team at Killer has helped notable institutions like Seattle Children’s Hospital, Seattle Cancer Care Alliance, and the Cleveland Clinic share their research stories and engage donors. Using industry examples, CEO Amy Balliett will show you how to develop successful visual content with tips and tricks that are budget friendly, targeted, and goal-oriented.  
In this session, you will learn:  
- How to identify where your research program communications falls short of visual authenticity and meaningful messaging and how to shift gears to succeed.  
- The process of designing an infographic from beginning to end  
- How to identify quality visual content that will convert so that you can avoid designing media that won’t.  
- How to develop dozens of pieces of custom and high-quality visual media without breaking the bank.  
**Moderator**  
Jenna Koschnitzky, PhD  
Director of Research Programs | Hydrocephalus Association |
| **Presenter**  
Amy Balliett  
Co-founder & CEO | Killer Infographics |
Lunch

**Open Science – Pre-registration: Approaches to ensuring reproducibility and transparency**

Reproducibility and transparency are critical elements to advancing biomedical research while providing scientists a tool for the future to better understand their data and outcomes. In this session, speakers will discuss the use of pre-registration and the strengths and challenges for funders to incorporate pre-registration as part of evaluation metrics. Perspectives for both non-clinical and clinical data will be presented to provide funders a comprehensive overview to determine how pre-registration may be a useful resource to ensuring that funded research projects are reproducible while encouraging our open science initiatives.

**Moderator**

Katrina Bandong, MS  
Program Associate for Medical Research | Doris Duke Charitable Foundation

**Presenters**

Tim Errington, PhD  
Metascience Manager | The Center for Open Science

Deborah Zarin, MD  
Director| ClinicalTrials.gov

**CONCURRENT BREAKOUT SESSIONS**

1- **INTERACTIVE WORKSHOP LED BY COS**

The Center for Open Science has created various ways by which research plans can be pre-registered. When you pre-register your research, you're simply committing to your plan in advance. Pre-registration allows researchers to stake their claim to their ideas earlier and can make the science better by increasing the credibility of the results. This workshop will introduce participants to the different ways in which scientists can pre-register their research, emphasizing easy to use pre-existing templates. Participants will also be introduced to recommended best practices. Though not required, participants are encouraged to prepare ahead of the workshop by thinking of studies that might be representative of the work that their grantees might pre-register.

**Presenter**

David Mellor, PhD  
Project Manager | Center for Open Science

2- **INTERACTIVE INFOGRAPHIC FOLLOW-UP**

You have your research results and now you need to get it in front of the right audience, but how do you represent the data in the best possible way? Visualizing information is a science in and of itself. It requires an understanding of visual communication best practices, design know-how, and the ability to create compelling data sets. In this session, you'll learn exactly what it takes by undergoing a series of hands-on and group think exercises related to communication design.

Through a series of 3 exercises, Amy Balliett will give you the tools you need to improve your own visual communication skills so that you can begin implementing what you've learned into your research reports immediately. In just 60 minutes you'll learn:

- How to communicate without text
- How to properly visualize data and data visualization mistakes to avoid
- How to manage a visual communication project from beginning to end

**Presenter**

Amy Balliett  
Co-founder & CEO | Killer Infographics
2:45 – 3:00 PM  
(15min)  
Break

3:00 – 4:15 PM  
(75min)  
**Intersection of Policy and Science: Advocating for Funding to Advance Research**

This session will provide examples of research advocacy between foundations, scientists, and policy makers. Ellie Dehoney, Vice President of Policy and Advocacy of Research!America will speak regarding her experience working with a range of different organizations. This session will also contain an HRA member panel in an effort to showcase different advocacy methods and levels of interaction with the political world. Speakers will cover experiences such as planning a Hill Day, advocacy via directly interacting with policy makers, and more indirect types of advocacy for organizations who need to remain politically neutral. Speakers will share the “how-to” of their advocacy program, including why a particular approach was chosen, challenges, outcomes, and best practices.

**Moderator**  
**Kara Coleman, PhD**  
Project Director, Biomedical Programs | Pew Charitable Trusts

**Presenter**  
**Ellie Dehoney, MPH**  
Vice President, Policy and Advocacy | Research!America

**Member Speakers**  
➤ **Laurie Whitsel, PhD**  
Director of Policy Research | American Heart Association

➤ **Jon Retzlaff, MBA, MPA**  
Chief Policy Officer, Vice President, Science Policy and Government Affairs | American Association for Cancer Research

➤ **Matthew Ellsworth, MFA**  
Vice President, Communications | The Flinn Foundation

4:15 - 4:45 PM  
(30min)  
**HRA News and Updates – open to all attendees**