

Spring 2016 HRA Members' Meeting - Executive Director Summary

HEALTH RESEARCH ALLIANCE
MEMBERS' MEETING

Co-Hosted by

Doris Duke Charitable Foundation

New York Stem Cell Foundation March 31 – April 1, 2016



MEETING AGENDA, PARTICIPANT LIST, SPEAKER BIOS, AND OTHER MEETING MATERIALS CAN BE FOUND ON THE MEMBERS' MEETING PAGE AT: [HTTPS://WWW.HEALTHRA.ORG/MEMBERS-ONLY/NEW-YORK/](https://www.healthra.org/members-only/new-york/)

SESSION 1: USE OF BIG DATA IN PRECISION MEDICINE: PATIENT & DISEASE SPECIFIC REGISTRIES

Speaker: **Amy Abernethy, MD/PhD**
Chief Medical Officer & SVP Oncology | Flatiron Health
www.flatiron.com

Talk title: **Big Data & Precision Medicine**
<https://www.healthra.org/wp-content/uploads/2016/03/Amy-Abernethy-New-York-Spring-2016-Meeting-Presentation.pdf>

To understand this topic, we need to rewind to IOM 2006, report from the Committee on Identifying and Preventing Medication Errors. (<http://www.nap.edu/read/11623/chapter/1#iv> .) Dr. Abernethy noted that avoid these errors, the care of a person should be informed by care of other patients that look like her/him. We have to rethink fundamental data structure to be able to do this because of the lightning speed that the variety and velocity of data is increasing.

Challenges:

1. Messy and unreliable clinical data
2. Instrumentation data (including genomics) is really “big”
3. Hard to follow a patient’s complete journey
4. Lack of real-world evidence making it hard to talk about expected outcomes

The critical tasks are to get the data:

- (1) organized
- (2) processed
- (3) readied for speedy analysis – so we can get to speedy results for patients

That’s Flatiron’s focus. Flatiron has built an Electronic Health Record (EHR) system that not only helps the doctor, and provides a critical data repository, but also moves from our current system of moving around digital images of paper records, to creating readily analyzable data. Flatiron’s system creates datasets that organize the data into stories, fill in the gaps when needed, and are ready for analyses at the push of an analytic button.

For Flatiron’s system, the EHR is the 1st data source. It is the start of a longitudinal diagnostic and treatment record. Structured data is not even consistent from clinic to clinic, but the most useful data is “unstructured data” – the data on the pdfs (the doctors’ notes, pathology report, NextGen sequencing data, etc). Flatiron uses algorithms **and people** to pull out key data points from unstructured documents and turn it into high quality analyzable information

creating highly curated datasets. That role for people looking at documents is important – but Flatiron uses technology to make that more efficient and accurate.

Flatiron uses “structured data processing” to increase consistency across records. They map terms to common standardized vocabulary and use algorithms and data processing to predict matches and match terms. So all the different ways albumin levels are measured (for instance) can be compared to each other.

But they also can capture key data from unstructured notes (e.g. faxes of physician’s notes) by using real people along with technology to extract key information and turn it into high quality analyzable information – creating highly curated datasets.

Amy’s conclusions:

- Harnessing data for our future means that we have to get the underlying infrastructure right.
- We need to take out the time for dataset preparation and focus our time on analyses.
- And the analyses have to be accurate – and also clinically actionable.

SESSION 1B: HRA MEMBERS’ BIG DATA PRESENTATIONS

Speaker 1: Shawn Sweeney, PhD

Associate Director of Translational Research | AACR Foundation

Talk title: Project GENIE – Genomics Evidence Neoplasia Information Exchange

<https://www.healthra.org/wp-content/uploads/2016/03/Shawn-Sweeney-New-York-Spring-2016-Meeting-Presentation.pdf>

Description of GENIE:

- Genie is an international cancer registry composed of CLIA/ISO-certified tumor sequences from patients treated at 7 centers
- The project goals are to:
 - Improve clinical decision-making by linking clinical genotypes with clinical phenotypes
 - Catalyze clinical and translational research
- Each member gets to look at their own data for 6 months, then the consortium sees it for 6 months – then the data will be made publicly accessible.

Data Sharing through GENIE

- GENIE harmonizes participants’ datasets through bioinformatics – no need for a common platform.
- Germline data is excluded in order to facilitate sharing fully de-identified data (big compromise).
- Each participant retains exclusive access to their data prior to consortium access and public access.
- Each participant retains exclusive access to its medical records and only the necessary clinical data elements are shared.
- Three subcommittees manage essential processes (due to legal issues):
 - Data Use and Membership
 - Concept Proposals and Publication
 - Data Standards

Speaker 2: Mathew Pletcher, PhD

Vice President of Genomic Discovery | Autism Speaks

Talk title: MSSNG: Changing the future of autism through open science

<https://www.healthra.org/wp-content/uploads/2016/03/Mathew-Pletcher-New-York-Spring-2016-Meeting-Presentation.pdf>

MSSNG is a public-private partnership between Google, Sick Kids Hospital and Autism Speaks to improve understanding and treatment of autism.

At least 10,000 whole genome sequences and deep phenotype data from families with autism

Data made freely available through open-access web-based portal

MSSNG lives in the Google cloud

Sequences go straight to the cloud and researchers are provided with different access. Researchers can perform computational analysis, if they have that skill set, or just query the data. If you are a genetic counselor you can search by variant - - phenotypes and genotypes are shown.

Balancing openness with protection of donors:

Autism Speaks controls all data access:

- Researcher applies for access
- Autism Speaks reviews application
- Approval of applications by DACO
- Autism Speaks adds the researcher to the MSSNG-research-read-access group

Limitations on access:

- Institutional co-signatures
- IRB-approved protocol
- Research must focus on autism and related diseases

Current status of MSSNG:

- 6,345 genomes sequenced and being uploaded to the Google cloud
- Over 1,204 additional samples in the queue
- 10,000 genomes completed by summer of 2016
- Nature Medicine Article and two additional scientific papers currently in review (1 NOT by Sick Kids researchers)

Speaker 3: Pam Feliciano, PhD

Scientific Director of SPARK | Simons Foundation

Talk title: SPARK: Accelerating Research and Improving Outcomes in Autism Spectrum Disorder

<https://www.healthra.org/wp-content/uploads/2016/04/Pam-Feliciano-New-York-Spring-2016-Meeting-Presentation.pdf>

SPARK enables anyone in US with a professional diagnosis of autism to register, consent, and provide saliva without ever leaving their house.

Enables a long-term partnership with thousands of families and keeps them engaged.

The requirements for participation in SPARK are (1) diagnosis of autism (2) participants agree to be re-contacted for other research studies.

SPARK is a bridge between participants and researchers, so participants feel engaged and like they benefit by participating, and researchers are more efficient and can spend less time recruiting and more time on the hard scientific problems.

SPARK's benefits for individuals and families affected with autism:

- Participants are partners, not subjects
- Commitment to return individual genetic results related to autism to medical professional that participant designates
- Return individual results on standardized behavioral questionnaires
- Inform community of aggregate results
- Opportunities to interact with autism experts online

SPARK's benefits for the research community:

- Full understanding of the genetic architecture of autism
- Enable more efficient recruitment (even genotype-based) to entire research community at no cost
- All behavioral and genetic data will be made accessible to any qualified researcher
- Some embargoes on entire genetic dataset but data will be released quickly after it is generated

Genetic analysis in SPARK:

- Exome sequencing of trios to accelerate gene discovery
- Sequencing of unaffected siblings when possible
- State of the art genome-wide genotyping for GWAS
- SPARK genomics consortium will analyze first 10,000 families

Current status of SPARK:

- Wrapping up pilot phase (recruitment of 500 trios)
- National launch on April 21
- Release data in scheduled releases beginning in Q3, 2016
- Open cohort to recruitment by research community in 2016
- Recruit and collect specimens from at least 10,000 trios through April 2017
- Report on pilot and genetic analysis of first 10,000 families

POTENTIAL HRA ACTION ITEM: (From the discussion) The idea of big data and how it translates to probability is important yet poorly understood. A recent paper (Ioannidis, Journal of Clinical Epidemiology, 2016) looked at the p value and how it has been interpreted, but this idea is not completely accurate. There could be a role for HRA to help set the standard around this discussion.

SESSION 2: APPROACHES TO ACHIEVE GENDER EQUITY IN STEM FACULTY: SUCCESSES, HURDLES AND OPPORTUNITIES FOR COLLABORATION

Speaker 1: Stephanie Abbuhl, MD

*Professor & Vice Chair Faculty Affairs, Department of Emergency Medicine
Executive Director, FOCUS on Health & Leadership for Women*

www.focusprogram.org

University of Pennsylvania Perelman School of Medicine

Talk Title: Women in Medicine and Biomedical Research

<https://www.healthra.org/wp-content/uploads/2016/03/Stephanie-Abbuhl-New-York-Spring-2016-Meeting-Presentation.pdf>

Part I: What the Data on Gender Diversity Show:

Even in 2014 studies, there are progressively fewer women as one goes up the academic ladder.

At US medical schools in the US, 79% of full professors are men while only 21% are women.

Our trainees see women in faculty roles at medical schools, but not in senior positions.

Women make up 38% of total faculty in medical schools but only 5% of all women faculty at medical schools are full professors.

Several studies show same disturbing trends. The common belief is:
“We just need to wait for all the women in the pipeline to advance.”

However, Dr. Abbuhl convincingly demonstrated using longitudinal data from several studies ¹ that;
“It’s not a “waiting” problem - It’s an advancement problem.”

- In US medical schools, women are less likely to be full professors after accounting for age, experience, specialty, and measures of research productivity.
- These sex differences held across all specialties.
- They did not vary by school research funding ranking.
- Junior faculty women received significantly less start-up support from their institutions than men.
- The discrepancies were not explained by degree, years of experience, or institutional characteristics.

The 5 Main Causal factors Putting Women at a Cumulative Disadvantage are:

1. Unconscious Bias

- Most people believe they are objective; however, both men and women give lower ratings when work is thought to be a woman’s. ²
- Tenured or tenure-track faculty members in the departments of biology, chemistry, and physics were significantly more likely to hire a man, pay him a higher salary, and see him as more worthy of mentoring — a bias that was equally strong among female and male scientists, and did not vary by age, race, or discipline. ³
- The very assertiveness necessary to overcome these barriers is perceived as unacceptable female behavior. ⁴

2. Salary Discrepancies

- Women earned an average of 11% less than men, even after adjustment for specialty, hours worked, etc. ⁵
- Women’s deficits are greater for those with more seniority. ⁵
- For Early Career MD Researchers (2010-2011 NIH K08 & K23 awardees), women averaged \$10,921 less, even after adjusting for appropriate variables. ⁶

3. Mentoring

- Academic faculty cite mentoring as critical to their success
- Women have perceived lower rates of effective mentoring – which they reported as an obstacle to career advancement. (Sponsors are key to success yet women don’t receive this type of mentorship.)
- Mentoring gaps include negotiation skills and work-life balance. ⁷

POTENTIAL HRA ACTION ITEM: Develop pilot strategies for incorporating a “SPONSORSHIP MODEL” into award mechanisms. “Sponsors differ from traditional mentors/coaches in that Sponsors have the position and power to advocate publicly for the advancement of nascent talent, including women, in the organization. Although academic medicine differs from the corporate world, the strong sponsorship programs that have advanced women into corporations’ upper levels of leadership can serve as models for sponsorship programs to launch new leaders in academic medicine.”

4. Work-Life Balance

- Long work hours
- Women in caregiving role disproportionately
- Technology makes 24/7 jobs

5. Culture

- Dual Career Couples – 86% of women have a working spouse yet 45% of men have a working spouse. ⁸
- Men worked 7 hours longer and spent 12 hours less on parenting/domestic tasks.
- Among spouses who both worked full-time men spent 9 hours less on parenting/domestic than women.
- There have been NO changes in 2 decades.

POTENTIAL HRA ACTION ITEM: Develop creative interventions to reduce the conflict between fulfilling both professional and parental roles. "Data show this could have substantial impact on improving the ability of early career scientists (particularly women) to succeed in science."

**Part II: Experiments into effective Interventions:
The NIH-TAC Trial ; Transforming Academic Culture**

Hypothesis:

Among women assistant professors, a multi-faceted intervention will do 3 things:

- Improve academic productivity (publications, grants)
- Improve self-efficacy & improve culture
- Decrease work-family conflict

Long term goal:

To create an environment where women can succeed fully in their careers, thus maximizing their contributions to academic medicine and improving workplace for all faculty.

Caveats:

- Very public trial possibly had an impact across the entire school
- No release time for intervention faculty
- Academic productivity may not be the most meaningful outcome
- Only 2 months of follow-up

Results:

Both intervention and non-intervention groups improved significantly in:

- Total # of peer reviewed publications
- Grant status
- Work-family conflict scores
- Work self-efficacy scores
- Department culture scores

However, intervention faculty decreased work hours while sustaining academic productivity.

NEXT STEPS: PENN FACULTY PATHWAYS PROGRAM - A CAREER LEADERSHIP PROGRAM FOR STEM ASSISTANT PROFESSORS

3 Goals: (1) Maximize Faculty Potential (2) Leadership Skills: Personal/Professional, and (3) Build Cohort Community

Year 1 – 8 Sessions

Inside Leadership	Promotion Strategies
Total Leadership Part I	Time Management
Total Leadership Part 2	Effective Communication
Total Leadership Part 3	Career Mapping

Year 2 – 4 sessions

Stress Management	Negotiation Strategies
Leadership Styles	Refreshing Career Map

Early Evaluation shows increases in:

- confidence in leadership
- confidence in negotiation
- planning career goals

ADDENDUM:

Listed below are additional potential “action items” for HRA sent by Dr. Abbuhl after the meeting. These interventions address the 5 key causal factors.

1. Unconscious bias.

- Consider having reviewers take the one-day unconscious bias training at Harvard (or the 4-day train the trainer program):

<https://www.aamc.org/initiatives/diversity/322996/lablearningonunconsciousbias.html>

2. Salary inequities

- Require grant applicants to demonstrate that their institutions have made efforts to review salaries for gender equity—including that the Chair/Chief of the department/division has signed off on a salary that has been reviewed and is fair and comparable to others with equivalent responsibilities.

3. Mentorship

- Require a short document from the mentor that highlights their plan for mentorship including how they will address the sponsorship issues—e.g. using the mentor’s significant professional power and influence to pave the way for career opportunities for the mentee.
- Ask specifically about leadership/faculty development programs and request that the applicant be enrolled in one and provided sufficient release time from other obligations (rather than just more requirements added to the already-too-full-plate) to participate.

4. Managing Work-Life Balance/integration

- Request that the institutions supply their work-life and family-friendly policies that apply to the applicant.
- Inquire specifically about maternity and paternity leaves, lactation space, and on-site or near-by day-care availability.
- Inquire specifically about administrative assistance provided by the department/division.

5. Culture

- Ask what the department’s initiatives for gender equity have been over the past 3 years and request the current gender breakdown of key leadership positions and senior academic ranks.
- Ask if there are intermittent “culture surveys”; when was the last one was issued and did it lead to change initiatives? Are there plans for future surveys?

From Dr. Abbuhl:

“Asking these questions sends a strong message....that the HRA funders care about these issues and want to be reassured that the organization (both at the institution and department/division level) are working to ensure gender equity by addressing the culture and institutional policies/procedures —rather than just “fixing the women.”

Finally, and very important, the HRA members might consider funding much needed research in this area – experiments with creative initiatives and potential solutions – so that proper research can be done to develop, implement, and measure outcomes related to improving the culture and success of women biomedical researchers.”

Citations:

1. Tesch, JAMA 1995, Nonnemaker, NEJM 2000, Jena, JAMA, 2015, Sege, JAMA, 2015
2. Valian V. Why so slow: The advancement of women. Cambridge, MA:MIT Press, 1998; Moss-Racusin, PNAS, 2012
3. Moss-Racusin, PNAS, 2012
4. Butler & Geis (1990), J Person & Social Psychol; Carli, LaFleur & Loeber (1995) J Person & Social Psychol; - Heilman et al (2004) J Applied Psychol; Phelan et al (2008) Psych Women Quart
5. McMurry JE et al. J Gen Intern Med. 2000;15:372-80; Capek L et al. Plast Reconstr Surg. 1997;99:289-99; Dresler CM et al. Arch Surg. 1996;131:1128-33; Kaplan SH et al. N Engl J Med. 1996;335:1282-9; Wright AL et al. Acad Med. 2003;78:500-508; Ash AS et al. Ann Intern Med. 2004;141:205-212; Jagsi R et al. JAMA, 2012; 307:2410-2417
6. Jagsi et al; Acad Med; 2013
7. Files et al. J Women’s Health; 2008; Blood et al. J Women’s Health; 2012; De Castro R et al. Acad Med; 2014
8. Jolly S et al. Ann Intern Med 2014

Speaker 2: Moses Chao, PhD

*Professor, Department of Cell Biology; Professor, Department of Neuroscience and Physiology;
Professor, Department of Psychiatry, Skirball Institute, New York University*

Talk Link: <https://www.healthra.org/wp-content/uploads/2016/03/Moses-Chao-New-York-Spring-2016-Meeting-Presentation.pdf>

The statistics regarding women in training vs. senior positions has not changed since 2000:

- There is a significant drop off in number of women between graduate and postdoctoral training (54-56% of trainees) and tenure track (29%)
- Women represent only 23% of Full professors and 19% of Chairs
- Women are promoted less, paid less, win fewer grants and receive fewer invitations to speak
- Unconsciousness bias contributes significantly to inequality.

Recommendations for promoting and ensuring gender equality in STEM areas:

- A report card for each institution documenting female representation at each level
- Requirement for grant-giving organizations to base funding opportunities upon gender equality
- Achieve gender balance in review and speaker committees
- A supportive environment
- Monitor for unconscious bias

Speaker 3: Eric Nestler, MD/PhD

Professor and Chair Neuroscience, Professor Pharmacology and Systems Therapeutics | Mt. Sinai Medical Center

Talk Link: <https://www.healthra.org/wp-content/uploads/2016/03/Eric-Nestler-New-York-Spring-2016-Meeting-Presentation.pdf>

We have already tested time and it hasn't worked. It's not a pipeline issue it's a retention issue, and the "John vs Jennifer" bias has not changed.

Diverse Brains Initiative: Goals

Launch a year-long discussion: To make everyone aware of the barriers to recruitment and retention of women and minorities in neuroscience.

- To identify tangible steps to reduce such barriers.
- To improve everyone's appreciation of implicit biases and subconscious behaviors that limit success.
- Short-term: to improve everyone's sense of productivity and satisfaction within the FBI at Mount Sinai.
 - Serve as a template for other departments/institutes. Long-term: to increase the recruitment and retention (promotion) of women and minorities in neuroscience.

Suggestions for action:

Incorporate "Affirmative Attention." Be intentional about inclusion/diversity for every symposium, panel, dinner guest, Etc. If we don't, inherent bias in all of us will prevent diversity.

Alter peer review system - require a report card (see NYSCF presentation below). Be transparent and think about blinded review. Blinded review is the standard in other fields but not standard in biological sciences.

SESSION 2B: HRA MEMBERS' EXPERIENCES IMPLEMENTING PROGRAMS

Speaker 1: Louise Perkins, PhD

Chief Science Officer | Melanoma Research Alliance

Talk title: <http://www.curemelanoma.org/research/mra-research-awards/team-science/>

MRA and L'Oréal Paris collaborated to offer a Team Science Award for a woman-led team with the goal of attracting and supporting women who are conducting field-leading melanoma research. Multidisciplinary teams consisted of two or more established PIs and a young investigator with complementary expertise, but the team must be led by a woman. (There was an initial misconception that the whole team had to be women.)

The rationale was to increase the % of female leadership in the team awards. In the past, the % of individual female applicants was about 1/3rd but for the team science awards it was only 18%.

Program elements included:

- Required each team to have a formal mentor
- Increased # of female reviewers
- All team science applications judged together, but as part of review look at track record of working in teams. (Women led teams seemed to have more history of doing this.)

Results looking at all Team Applications:

- 20% of letter of intent before from women - this cycle 42% – a notable increase
- No pushback from review committee or anyone, especially since it was made clear that the science was paramount. (But it was a donor-led initiative.)
- Having a greater % of women reviewers may or not be helpful.

Speaker 2: Susan L. Solomon

Chief Executive Officer | New York Stem Cell Foundation

Talk title: <https://nyscf.org/research/iwise>

Genesis for creating Women in Science and Engineering (IWISE) was dissatisfaction with their own practices.

Goal of IWISE: Generate a shortlist of strategies to promote women in science, medicine, and engineering

The IWISE working group generated a list of 7 actionable strategies (listed below) for advancing women in science, engineering, and medicine. The full details of these recommendations were published in Cell Stem Cell, in March 2015.

Direct financial support strategies:

1. Implement flexible family care spending
2. Provide “extra hands” awards

Psychological and cultural strategies:

3. Recruit gender balanced external review and speaker selection committees
4. Incorporate implicit bias statements
5. Focus on education as tool

Major collaborative and international initiatives:

6. Create an institutional report card for gender equality that applicants need to submit (This is a very impactful intervention – they learned that it needs to be simple and standardized, something a department chair can complete, and care has to be taken so women applicants aren't penalized at institutions receiving a poor report card.)
7. Partner to expand upon existing searchable databases of women in science, medicine and engineering

POTENTIAL HRA ACTION ITEM: Convene a task force to look at all the recommendations from this session to come up with a set of recommended interventions and some ways to measure the impact of these interventions. One place to start is with the institutional report card. Do you have day care? What kind of mentorship/sponsorship program do you have? Another is to look at what is valued in applications. Women would score higher if higher value is placed on teaching, giving talks and seminars, collaborations and team science.

POTENTIAL HRA ACTION ITEM: Work together to create a database of women for review committees, meeting speakers, etc. The few women in leadership positions are asked to participate much more in conferences and committees and this comprehensive list would help extend these opportunities to other women, and not overburden those who are already being frequently asked.

POTENTIAL HRA ACTION ITEM ; Research the bias literacy workshop created by Molly Carnes. “Promoting Institutional Change Through Bias Literacy”. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3399596/> Is this worthwhile presenting to our membership?

SESSION 3: MEASURING AND MESSAGING RESEARCH OUTCOMES OF YOUR FUNDING

Speaker 1: Naba Bora, PhD

Program Manager, Congressionally Directed Medical Research Programs (CDMRP)
Department of Defense
<http://cdmrp.army.mil/>

Talk Title: A Storyboard Approach to Charting Research Progress and Demonstrating Impact

<https://www.healthra.org/wp-content/uploads/2016/04/Naba-Bora-New-York-Spring-2016-Meeting-Gender.pdf>

Goals of CDMRP Storyboarding:

- Identify gaps in research funding
- Assess impact of NFRP funding
- ID key advances in NF in visual format

Audience:

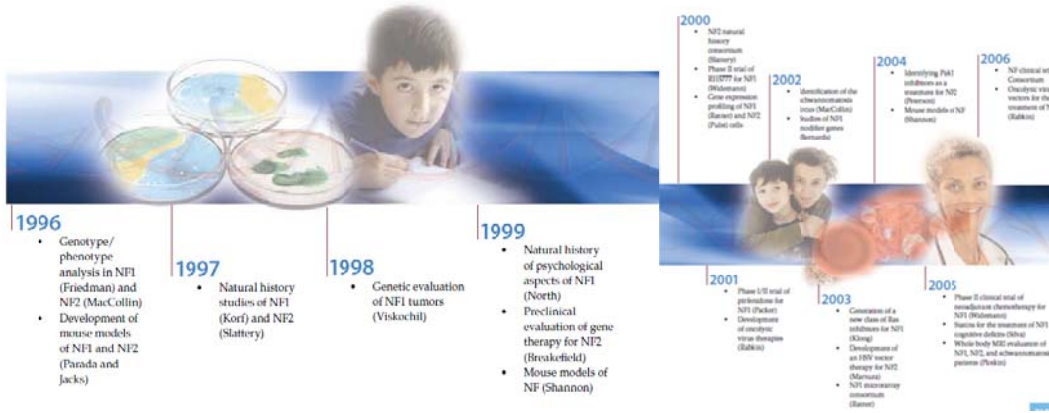
- Consumers (patients and advocates)
- Congress
- Programmatic panel
- CDMRP

Example 1: Process for developing Neurofibromatosis Storyboards

- Identify key research advances from publications, regardless of source of funding
- Identify research project results
- Map each project advancement to year
- Map to specific area of science (i.e.) Molecular biology, genetics, cell biology, pathobiology
- Map to disease type (looking at NF1 or NF2)
- Color coded for links between research

Examples of Findings via Storyboarding:

- More research advances in basic vs. clinical prior to 2004
- Most in area of molecular biology and genetics, cell biology and pathobiology, animal model development
- NFRP has had an impact in shaping the progress of NF research
- Gaps identified not necessarily a priority in NF research
- Primarily a retrospective tool to look at program accomplishments
- Not particularly useful for strategic decision making
- Useful as a PR tool



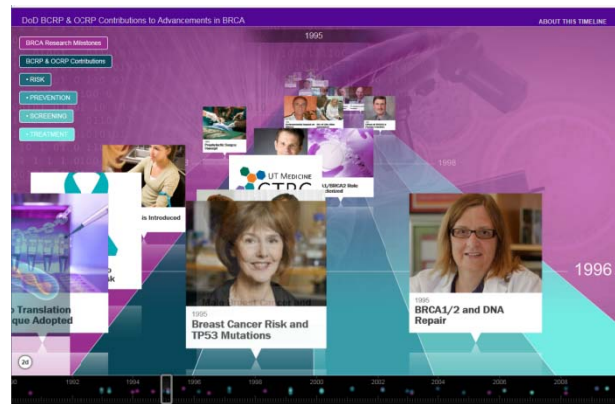
Example 2: Contributions to advances in BRCA research

Breast Cancer Research Program, Ovarian Cancer Research Program Using Tiki Toki (online toll to create dynamic storyboards/timelines)

<http://www.tiki-toki.com/>

http://cdmrp.army.mil/brca_timeline/default.shtml

Shown below are static screen shots of the dynamic timeline at the CDMRP website above.



Speaker 2: Jevin West, PhD

Assistant Professor, Information School | University of Washington
<http://www.jevinwest.org/>

Talk Title: Mapping the HRA Community

<https://www.healthra.org/wp-content/uploads/2016/03/Jevin-West-New-York-Spring-2016-Meeting-Presentation.pdf>

Measuring impact is a really tough problem. Though machine learning and data processing have increased the robustness of the measurement, it still needs human intervention. Jevin's team uses his "Eigenfactor" to measure influence. The Eigenfactor quantifies the value provided by academic journals using citations as the primary indicator of scholarly impact. There is at least one caveat however. "Men set their own cites high" meaning men cite their own work at much higher rates than women, skewing the Eigenfactor.

Scientists put too much focus on their own H Index impact which is a problem in that it then has too much influence in the reward structure which ultimately hurts science. There are other ways to look at publication data that is much more nuanced and measures things like interdisciplinarity. Who are the "integrators?"

By looking at the number of citations for a given author, from different fields, and over time, the West team uses the Eigenfactor to visualize:

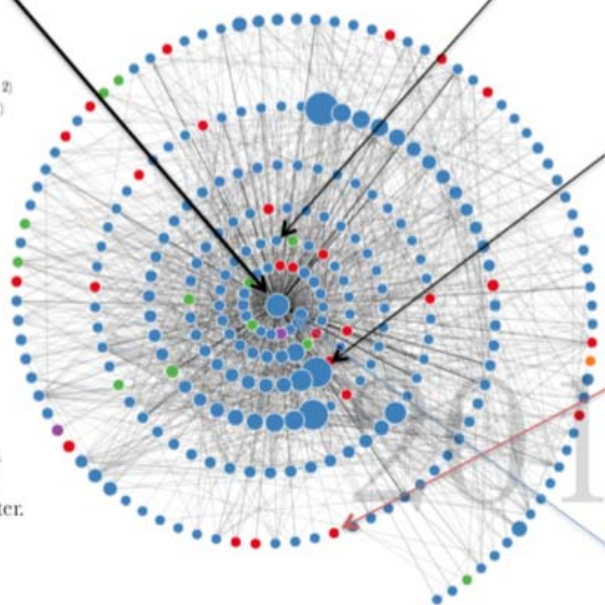
- Scholarly influence
- Funding impact
- Interdisciplinarity

The graphic below shows a network diagram that represents citations from many different fields as well as the relative number of citations from those fields over time.

The **center node** represents all of the papers authored by the scholar of interest.

Surrounding nodes represent papers that have cited work by the scholar of interest. Lines between the nodes show citations between papers.

- Papers in category "Biology" (domain 4)
- Papers in category "Medicine" (domain 6)
- Papers in category "Chemistry" (domain 5)
- Papers in category "Computer Science" (domain 2)
- Papers in category "Multidisciplinary" (domain 1)



Showing a scholar's influence

The size of each node is scaled by the *Eigenfactor score* of that paper—a metric of influence that takes into account its position in the total citation network. Bigger nodes represent the most influential papers that have cited the central scholar.

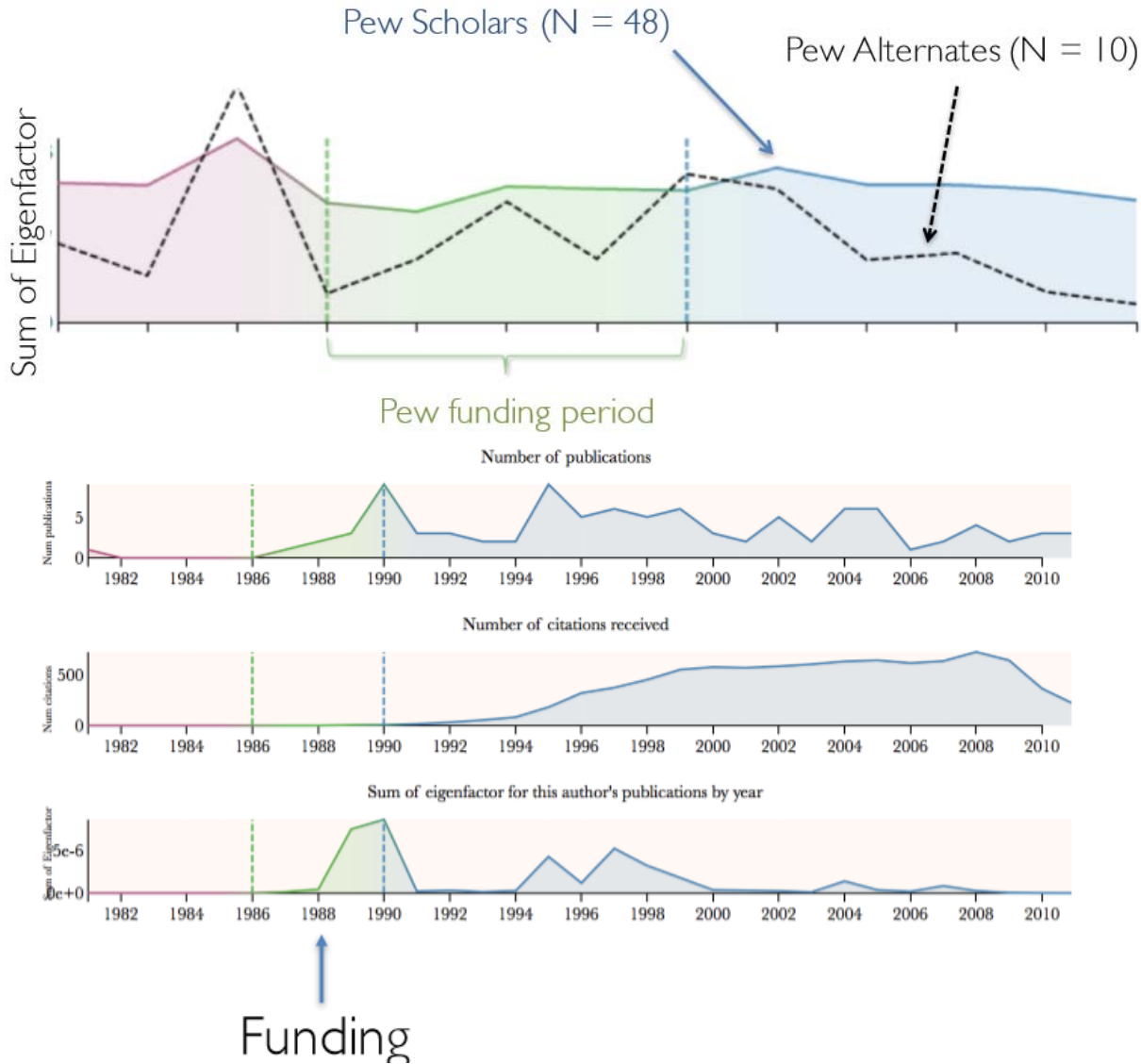
The color of each node shows the academic discipline of the paper. A more colorful network means that the impact of the central scholar's work has extended out to a wider range of fields.

The color of the center node represents the dominant field of the central scholar—the most common field of all the scholar's publications.

Papers are revealed by year in a spiral formation, so that earlier papers appear closer to the center.

PEW Scholars Example: Jevin’s team used the PEW Scholars program to visualize scholarly influence over time and measure funding impact.

Using Jevin’s methods, one can visualize (using the Eigenfactor) the impact of the PEW Scholars award at both the program level or at the individual level. This is possible because PEW has comparison group of those just below the cut line. This graphic shows or suggests that having the fellowship has an impact on the Eigenfactor, especially years after the funding.



Jevin would like to work with HRA members individually and the organization as a whole to create personalized visualization for different stakeholders (funders, researchers, donors.) Jevin could use HRA’s aggregate data to sample the whole consortia and look at issues like basic vs. applied research, model organisms, funding agencies, individual vs. collaborative grants, etc.

SESSION 4: TEAM SCIENCE TOOLS: PRACTICAL TEAM SCIENCE GUIDANCE

Speaker: **Holly Falk-Krzesinski, PhD**
Vice President, Strategic Alliances, Global Academic Relations | Elsevier

Talk Title: **Tools You Can use: Practical Team Science Guidance**
<https://www.healthra.org/wp-content/uploads/2016/03/Holly-Falk-Krzesinski-New-York-Spring-2016-Meeting-Presentation.pdf>

A team of expert is not necessarily an expert team. Effective teams take work.

There is increased demand for team science initiatives (academia and funding agencies)

- Short-term team science takes more time due to coordination costs
- Long-term there needs to be a payoff in terms of acceleration
- Thus it is imperative that we understand the most effective practices for productive cross-disciplinary collaboration and team science
- Once those practices are known then train investigators, institutional leaders, and funders to employ them.

Resources:

1. [Elsevier's Academic Executive Brief](#)
Authors from US, Germany, Malaysia and India describe team science tools relating to institutional and national influence, team science tools and leadership, team formation and research networking systems.
<http://academicexecutives.elsevier.com/volume-2-issue-2-2012>
2. [TeamScience.net](#)
An online learning tool to enhance skills needed to perform cross-disciplinary, team-based biomedical research. Module 1 provides a didactic yet interactive overview of the Science of Team Science. Modules 2-4 afford an experiential learning environment where the researcher can adopt different roles and engage virtually in the challenges of team research.
3. [The Toolbox Project](#)
A collaborative communication workshop to provide philosophical yet practical enhancement to cross-disciplinary, collaborative science. Workshop participants engage in small group discussion and share respective views in response to a number of probing statements about science motivation, methodology, confirmation, objectivity, values, and reductionism.
4. [Collaboration Success Wizard](#)
Online diagnostic survey for geographically distributed collaborations that probes factors that might strengthen or weaken the collaboration and helps build successful collaborative projects.
<http://hana.ics.uci.edu/wizard/index.php>
5. [Collaboration & Team Science: A Field Guide](#)
Covers: Overall Goals & Vision, Who Will Do What, Sharing/Storing Reagents & Data, Authorship, Credit, Contingencies & Communicating, and Conflict of Interest. <http://teamscience.nih.gov>

6. Team Science Toolkit

The Team Science Toolkit is an interactive website that provides resources to help users support, engage in, and study team-based research.

Discover: Learn from colleagues by exploring Toolkit resources contributed by other users

Download resources that can support your goals

Contribute: Share your knowledge of team-based research and the Science of Team Science (SciTS) field and upload resources such as documents and links, or comment on resources already in the database

Connect: Connect with colleagues who share your interest in team-based research through the expert blogs, news and events bulletin boards, expert directory, and listserv. www.teamsciencetoolkit.cancer.gov

7. SciTS Listserv

Listserv facilitates conversation those engaged in, studying, or managing team science, in the US and internationally. It is maintained by the SciTS Team at the National Cancer Institute, Division of Cancer Control and Population Sciences, Behavioral Research Program. (<http://cancercontrol.cancer.gov/brp/scienceteam>).

8. See Dr. Falk-Krzesinski's PowerPoint presentation for additional recommendations, tools from Elsevier (like the Mendeley Science of Team Science (SciTS) Group), and additional information about existing funding for team science (see the NIH Exploratory Center Grants, or the NSF Research Coordination Networks, etc.

9. The NAS report – “Enhancing the Effectiveness of Team Science.”

[HTTP://SITES.NATIONALACADEMIES.ORG/DBASSE/BBCSS/CURRENTPROJECTS/DBASSE_080231](http://SITES.NATIONALACADEMIES.ORG/DBASSE/BBCSS/CURRENTPROJECTS/DBASSE_080231)

SESSION 4B: HRA MEMBERS' EXPERIENCES IMPLEMENTING PROGRAMS

Speaker 1: Pat Morin, PhD

*Senior Director Scientific Review and Grants Administration | AACR Foundation
The SU2C Dream Team as a Model for Team Science.*

Talk Link: <https://www.healthra.org/wp-content/uploads/2016/03/Pat-Morin-New-York-Spring-2016-Meeting-Presentation.pdf>

- SU2C Dream Teams goal to accelerate innovative cancer research that has the potential to deliver new therapies to patients rapidly (in three years)
- The AACR is the Scientific Partner to SU2C, providing expert peer review, grants management, and scientific oversight
- This Program brings together top researchers worldwide and encourages collaborations (including with 57 companies) rather than competition in its funded projects
- Over \$230 million in grants to 19 Dream Teams, 2 smaller Teams, and 36 individual young investigators
- Key components are the in-person selection meeting and the in-person progress review visit (every 6 months)
- Challenges:
 - Inconsistencies in Contract Language and Submission of Reports
 - Discrepancies in Progress Reports and Financial Reports across Institutions
 - Intellectual Property
 - Delays in Contract Execution
 - Communications
 - Project Management

Speaker 2: Laura Brockway-Lunardi, PhD

Scientific Program Director | Melanoma Research Alliance

Talk Link: <https://www.healthra.org/wp-content/uploads/2016/04/Laura-Brockway-Lunardi-New-York-Spring-2016-Meeting-Presentation.pdf>

Team Awards are 2/3 of their portfolio in dollars, but only 1/3 in terms of number of awards.

- Multidisciplinary collaboration between two or more established PIs plus a Young Investigator with complementary expertise that offers the possibility for synergistic advances.
- Typically \$800,000-\$1 million total over 3 years
- Periodic “Special Opportunities” with different/more specific requirements

Benefits of teams:

- Collaboration
- Multidisciplinary science
- Build the field

Challenges of teams:

- Financial risk: Large investment over short timeline
- Administrative
- Leadership

Lesson learned:

- Demonstrate “team-ness” in applications
- 3 year award duration better than 2
- 60 day timeframe for sub-awards – helps avoid delays caused by inter-institutional negotiation
- Avoid post-review matchmaking

Speaker 3: Julie Milder, PhD

Associate Research Director | CURE | Citizens United for Research in Epilepsy

Talk Link: <https://www.healthra.org/wp-content/uploads/2016/03/Julie-Milder-New-York-Spring-2016-Meeting-Presentation.pdf>

The CURE Infantile Spasms Team Science Initiative

CURE’s first directed team-science initiative – 1/3 of annual research budget.

Program Goal: To support collaborative, milestone-driven efforts that lead to the development of a disease-modifying therapy or cure for infantile spasms.

The Team was composed of researchers with differing skill sets:

- Animal models and mechanisms
- Tool Development
- Human and Clinical Studies

Challenges:

- Milestone-driven vs. discovery science
- “Outside” guidance
- Maintaining open communication

Solutions:

- Collaborate
- Share
- Critique

THANK YOU!

THE HEALTH RESEARCH ALLIANCE WOULD LIKE TO THANK THE FOLLOWING ORGANIZATIONS AND INDIVIDUALS FOR THEIR VALUABLE CONTRIBUTIONS TO THE SPRING 2016 MEMBERS' MEETING

MEMBERS' MEETING CO-CHAIRS:

Pat Morin, PhD.

Margaret Laurence

MEETING CO-HOSTS:

Doris Duke Charitable Foundation



New York Stem Cell Foundation



LUNCH SPONSORS:

Iacocca Family Foundation



Simons Foundation

SIMONS FOUNDATION

SPEAKER TRAVEL SPONSOR:

Pancreatic Cancer Action Network



Spring 2016 HRA Members' Meeting - Executive Director Summary

HEALTH RESEARCH ALLIANCE
MEMBERS' MEETING AGENDA

Co-Hosted by

Doris Duke Charitable Foundation

New York Stem Cell Foundation

March 31 – April 1, 2016



March 31 | Thursday

10:00 - 10:30 AM

Welcome to the Members' Meeting and Introductions

Program Committee Co-Chairs

Margaret Laurence

Executive Director | The Iacocca Family Foundation

Pat Morin, PhD

Senior Director, Scientific Review and Grants Administration | AACR Foundation

HRA Board Chair

Betsy Myers, PhD

Program Director for Medical Research | Doris Duke Charitable Foundation

10:30 AM–12:00 PM

Use of Big Data in Precision Medicine: Patient & Disease-Specific Registries

"Big data" means different things to different people, depending on context. For the purpose of this session, we choose to focus on big data as it pertains to registries of genomic data. These registries can focus on healthy populations, patient populations, specific diseases, or some combination. We are interested in learning how these vast pools of genomic data can act as a basis for a community gathering of patients sharing data and disease experiences; how they can be utilized to improve health care delivery and clinical outcomes; how they can be mined to formulate and test disease hypotheses; and how they can inevitably contribute to disease eradication. In addition, genomic datasets may identify pre-disease states and therefore may predict who will develop disease and who will remain healthy. As the registry movement is still in its infancy, important issues such as patient privacy, data security, and the question of open access still need to be addressed. Our main speaker and several member organizations will provide presentations to address these and other facets of this complicated topic.

Moderator

Mary DeRome

Translational Research Manager | Multiple Myeloma Research Foundation

Presenter

Amy Abernethy, MD/PhD

Chief Medical Officer & SVP Oncology | Flatiron Health

Member Panelists

➤ **Shawn Sweeney, PhD**

Associate Director of Translational Research | AACR Foundation

➤ **Mathew Pletcher, PhD**

Vice President of Genomic Discovery | Autism Speaks

➤ **Pam Feliciano, PhD**

Scientific Director of SPARK | Simons Foundation

12:00–1:30 PM

Lunch: co-sponsored by the **Iacocca Family Foundation** and the **Simons Foundation**

Interest Group Discussions over Lunch (open to all meeting participants)

The Discovery Science and Early Career Scientist Interest Groups are hosting round table discussions over lunch on key topics of interest. There is also space available for a networking lunch.

1:30 - 3:00 PM

Approaches to achieve gender equity in STEM faculty: successes, hurdles and opportunities for collaboration

This session will present data on gender inequities in STEM faculty and on the new interventions that academia and funders have implemented to promote retention and advancement of female faculty conducting research on human health. Panelists will share about the success and hurdles in the implementation of these interventions to identify opportunities for funders to strengthen academia's efforts to achieve gender equity in STEM faculty.

Moderator

Sindy Escobar-Alvarez, PhD

Program Officer for Medical Research | Doris Duke Charitable Foundation

Presenters

Stephanie Abbuhl, MD

Professor and Vice Chair of Faculty Affairs, Department of Emergency Medicine and Executive Director of FOCUS on Health & Leadership for Women | University of Penn School of Medicine

Moses Chao, PhD

Professor, Department of Cell Biology; Professor, Department of Neuroscience and Physiology; Professor, Department of Psychiatry, Skirball Institute | New York University

Eric Nestler, MD/PhD

Professor and Chair Neuroscience, Professor Pharmacology and Systems Therapeutics | Mt. Sinai Medical Center

3:00 - 3:15 PM

Members' Experiences Implementing Programs

➤ **Louise Perkins, PhD**

Chief Science Officer | Melanoma Research Alliance

➤ **Susan L. Solomon**

Chief Executive Officer | New York Stem Cell Foundation

3:15 - 3:45 PM

Break

3:45 - 4:45 PM

"Gene Editing and Precision Medicine" Scientific Session

Dr. Zhang is a bioengineer who has pioneered the development of genome editing tools for use in eukaryotic cells – including human cells – from natural microbial CRISPR systems. These tools, which he has made widely available, are accelerating biomedical research around the world. Dr. Zhang leverages CRISPR and other methodologies to study the role of genetic and epigenetic mechanisms underlying diseases, specifically focusing on disorders of the nervous system. His methods are also being used in the fields of immunology, clinical medicine, cancer biology, and other research areas. This technique for mammalian genome editing has had enormous impact on experimental science and holds great promise for therapeutic applications as well. In 2015, Science named CRISPR the "Breakthrough of the Year."

Moderator

Yung Lie, PhD

Deputy Director and Chief Scientific Officer | Damon Runyon Cancer Research Foundation

Presenter

Feng Zhang, PhD

Core Member, Broad Institute of MIT and Harvard | Investigator, McGovern Institute for Brain Research, Massachusetts Institute of Technology | W. M. Keck Career Development Professor in Biomedical Engineering, Departments of Brain and Cognitive Sciences and of Biological Engineering, Massachusetts Institute of Technology | Robertson Investigator, New York Stem Cell Foundation

- 4:45 - 5:30 PM** **Host Session—DDCF and NYSCF**
Host comments
- **Betsy Myers, PhD**
Program Director for Medical Research | Doris Duke Charitable Foundation
 - **Susan L. Solomon**
Chief Executive Officer | New York Stem Cell Foundation

5:30 - 6:15 PM **Break** - Meet in Hotel Lobby at 6:15pm

6:30 -10:00 PM **Reception and Dinner at Michael’s Restaurant (24 W 55th Street)**

April 1 | Friday

8:30 - 9:30 AM **Interest Group Discussions over Breakfast (open to all meeting participants)**
The Grants Administration and Drug and Other Therapy Development Interest Groups are hosting round table discussions over breakfast on key topics of interest. There is also space available for a networking breakfast.

9:30 -10:30 AM **HRA News and Updates**
Comments from the HRA Board Chair
Betsy Myers, PhD
Program Director for Medical Research | Doris Duke Charitable Foundation

Update on the Strategic Planning process
Kevin Lee, PhD
Executive Director | Lawrence Ellison Foundation

Update on gHRAsp
Lorraine Egan, PhD
President and CEO | Damon Runyon Cancer Research Foundation

Update on the Open Science Task Force
Sindy Escobar-Alvarez, PhD
Senior Program Officer | Doris Duke Charitable Foundation

Update on the HRA-FDA Distinguished Lectureship Series
Maryrose Franko, PhD
Executive Director | Health Research Alliance

Update on the Members’ Meeting Task Force
Pat Morin, PhD
Senior Director, Scientific Review and Grants Administration | AACR Foundation

10:30 - 12:00 PM **Measuring and Messaging Research Outcomes of Your Funding:**
The session focuses on innovative approaches that funders can use to evaluate and measure the scientific outcomes of their research grants, and complements previous evaluation sessions that have been offered at HRA meetings. Both qualitative and quantitative strategies will be presented to measure short- and long-term research discoveries and advances that result from individual research grants and from clusters of grants that focus on specific research topics. Data visualization strategies also will be presented to show how to effectively translate progress, and shape and communicate messages about research outcomes to different stakeholders, including donors, patients, Board members as well as the scientific community. Speaker presentations will be followed by small group breakout sessions that focus more sharply on each of the different strategies and include exercises for participants to get first-hand experience on how these tools are actually implemented and can be applied to their area of funding.

Moderator

Rhonda Aizenberg, PhD

Director, Research Grants Department, Scientific & Medical Affairs | Pancreatic Cancer Action Network

Presenter(s)

Naba Bora, PhD

Program Manager, CDMRP | Department of Defense

Jevin West, PhD

Assistant Professor, Information School | University of Washington

Q&A and Instructions for exercises

12:00 - 1:30 PM

Hands-on Data Visualization Exercises over Lunch or Networking Lunch

1:30 - 3:00 PM

Team Science Tools: Practical Team Science Guidance

Team science initiatives are characterized by cross-disciplinary collaboration focused on outcome-oriented research. Over the last decade, academia has generated an upsurge in team science initiatives, while external funding agencies in the United States and around the globe have made more collaborative and team-based science funding opportunities available. Studies on research centers funded by the National Science Foundation (NSF) and National Institutes of Health (NIH) have demonstrated that team science initiatives entail significant coordination costs. As a result, team science takes more time, at least proximally, than individual research; however, studies have also demonstrated a distal payoff in terms of research acceleration. Consequently, it is imperative that stakeholders of team science understand the most effective practices for productive team science and learn to employ them. Drawing from a rich evidence base, this topic will present a collection of practical tools and resources that foundation funders can draw upon to implement effective practices in team science. The presenter will cover:

- ☐ An overview of the literature in the science of team science;
- ☐ Leadership for team science;
- ☐ Team science communication;
- ☐ Team science evaluation; and,
- ☐ Reward and recognition for collaborative science.

HRA member representatives will present tips and lessons learned from their own experience with team science. Please read the background on the related projects in advance.

Moderator

Belinda Orland, MBA

Senior Manager, Research Evaluation and Reporting | American Heart Association

Presenter

Holly Falk-Krzesinski, PhD

Vice President, Strategic Alliances, Global Academic Relations | Elsevier

Member Presentations

➤ **Pat Morin, PhD**

Senior Director Scientific Review and Grants Administration | AACR Foundation

➤ **Laura Brockway-Lunardi, PhD**

Scientific Program Director | Melanoma Research Alliance

➤ **Julie Milder, PhD**

Associate Research Director | CURE | Citizens United for Research in Epilepsy

3:00 - 3:15 PM

Wrap-Up and Adjourn

Program Committee Co-Chairs

Margaret Laurence

Executive Director | The Iacocca Family Foundation

Pat Morin, PhD

Senior Director, Scientific Review and Grants Administration | AACR Foundation

HRA Board Chair

Betsy Myers, PhD

Program Director for Medical Research | Doris Duke Charitable Foundation