

Progress through Partnership: The NINDS 2016 Nonprofit Forum

Lister Hill/Natcher Conference Center

National Institutes of Health

September 13-14, 2016

Day 1 Tuesday, September 13, 2016

- 9:30-10:00 a.m. **Registration**
- 10:00-10:30 a.m. **NINDS Director's Welcome**
Walter Koroshetz
- 10:30-11:15 a.m. **Lessons Learned and Case Studies in Natural History Databases***
Panel discussion
- Moderators: Petra Kaufmann (NCATS), Janet Hieshetter (Dystonia Medical Research Foundation)
Speakers: Steve Kaminsky (International Rett Syndrome Foundation), Michael Shy (University of Iowa), Steve Roberds (TS Alliance)
- 11:15-11:30 a.m. **Break**
- 11:30 a.m.-
12:15 p.m. **Data Integration and Data Management: Challenges and Opportunities***
Lessons Learned in Data Sharing from Repositories
- Moderator: Paul Gross (Hydrocephalus Association)
Speakers: Greg Farber (NIMH), Shawn Murphy (Harvard Medical School), Tamara Simon (University of Washington)
- 12:15-1:00 p.m. **Strategies for Biomarker Identification***
Panel discussion
- Moderators: Katrina Gwinn (NINDS), Hao Wang (NINDS)
Speakers: Petra Kaufmann (NCATS), Shashi Amur (Biomarker Qualification Program, FDA/CDER), Bill Potter (NIMH)
- 1:00-1:45 p.m. **Lunch Break**
- 1:45-2:30 p.m. **NIH 101: Priority Setting, Decision-Making, NIH Basics and Discussion**
Alan Willard (NINDS)
- 2:30-3:30 p.m. **Developing Better Clinical Outcome Measures***
Integrating Patient-Reported Outcomes, Wearable Technologies, and FDA Needs into Clinical Data Collection

Moderator: Ron Bartek (Friedreich's Ataxia Research Alliance)
Speakers: Ray Dorsey (University of Rochester), Carsten Bonnemann (NINDS), Michael Shy (University of Iowa), Matthew Goodwin (Northeastern University), Jacob Kean (University of Utah)

3:30-5:00 p.m. **Meet the Program Directors**

5:00-6:00 p.m. **NPO-sponsored Reception**

Day 2 Wednesday, September 14, 2016

8:30-10:30 a.m. **Concurrent Breakout Sessions** *Select two from the list below (Session 1 runs from 8:30-9:30 a.m. and Session 2 runs from 9:30-10:30 a.m.). The sessions will be held at the Natcher Conference Center.*

Strategies for Biomarker Identification

Moderator: Katrina Gwinn (NINDS) and Hao Wang (NINDS)

Developing Better Clinical Outcome Measures

Moderator: Ron Bartek (Friedreich's Ataxia Research Alliance)

Focus on Ultra-Rare Diseases

Moderator: Jill Morris (NINDS)

10:30-10:45 a.m. **Break**

10:45-11:30 a.m. **Breakout Session Reports**

11:30 a.m.-
12:30 p.m. **Poster Session**

12:30-1:30 p.m. **Lunch**

1:30-2:30 p.m. **Cultivating Collaborations on a Shoestring and Investing in the Intellectual Pipeline**
Building a Multi-Stakeholder Network from Ground Zero & Best Practices for Finding, Funding and Retaining Researchers

Moderator: Cynthia Rothblum-Oviatt (A-T Children's Project)

Speakers: Carsten Bonnemann (NINDS), Tish Hevel (Brain Donor Project), Salvatore La Rosa (Children's Tumor Foundation), Jenna Koschnitzky (Hydrocephalus Association)

2:30-3:30 p.m.

Featured Success Stories

Lessons Learned from Leveraging Resources, Network Building, and Strategic Planning into Successful Business Models

Moderator: Walter Koroshetz

Speakers: Gordon Gray (Charlotte and Gwennyth Gray Foundation), Keith Fargo (Alzheimer's Association), Alex Klein (Cure PSP)

3:30 p.m.

Adjourn

*The following representatives from industry have been invited to provide perspectives on panel discussions:

- Ronald Marcus, Cerecor
- Sean Ekins, Phoenix Nest Biotech