**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**

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Presenter/Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30-10:00 a.m.</td>
<td>Registration</td>
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<tr>
<td>10:00-10:30 a.m.</td>
<td>NINDS Director’s Welcome</td>
<td>Walter Koroshetz</td>
</tr>
</tbody>
</table>
| 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 Gwenyth 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