

Progress Through Partnership:
The NINDS Nonprofit Forum
September 10-11, 2013

Tuesday, September 10

Noon-12:30 p.m.	Registration	Location: Atrium
12:30-1:00 p.m.	NINDS Director's Welcome and Overview	Location: Balcony C Dr. Story Landis, Director, NINDS
1:00-1:30 p.m.	Engaging Patients in Clinical Research	Dr. Petra Kaufmann, Associate Director for Clinical Research, NINDS
1:30-2:00 p.m.	The BRAIN Initiative	Dr. Kathy Hudson, Deputy Director for Science, Outreach and Policy, NIH
2:00-2:15 p.m.	Break	
2:15-3:30 p.m.	Meet NINDS Program Directors	Location: Conference Rooms C1, A
3:30-5:00 p.m.	Nonprofit Success Stories	Location: Balcony C Moderator: Dr. Landis Panelists: Susan Dickinson, Executive Director, The Association for Frontotemporal Degeneration Dr. Jan Teller, Chief Scientific Officer, Dystonia Medical Research Foundation Susan Axelrod, Chair and Founding Member, Citizens United for Research in Epilepsy (CURE) Amy Rick, Chief Executive Officer, Parkinson's Action Network (PAN)
5:00-6:00 p.m.	Nonprofit Organization Reception	Location: Conference Room G1

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8:00-9:00 a.m.	What Does the NINDS Advisory Council Do? Perspectives From Council Members	Location: Balcony C Moderators: Dr. Alan Willard, Deputy Director, Division of Extramural Research, NINDS and Amy Rick, Chief Executive Officer, PAN Panelists: Dr. David Ginty, Professor, JHU School of Medicine, Howard Hughes Medical Institute Paul Gross, Past Chairman, Hydrocephalus Association Dr. Kevin McNaught, Vice President, Medical & Scientific Programs, Tourette Syndrome Association
9:00-9:15 a.m.	Break	
9:15-9:30 a.m.	Small Business Program at NINDS	Stephanie Fertig, Research Project Manager, NINDS
9:30-11:00 a.m.	Plenary Session: News from NIH and FDA	
	Rare Diseases Consortium; Compound Repurposing	Dr. Stephen Groft, Director, Office of Rare Diseases, NCATS, NIH
	FDA: Patient Focused Drug Program	Andrea Tan, Operations Research Analyst, Center for Drug Evaluation and Research, FDA
	FDA Program/Patient Perspective	Patricia Furlong, Founding President and CEO, Parent Project Muscular Dystrophy

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11:00-11:15 a.m.	Break
11:15 a.m.-Noon	Evaluation and Conclusion
Noon-1:00 p.m.	Lunch on your own

Non-Governmental Organizations Afternoon Session

Location: (Balcony C)

1:00-1:20 p.m.	Welcome and Introduction
1:20-2:15 p.m.	NINDS Budgets Dollars for Diseases: The Good, the Bad and the Ugly
2:15-3:50 p.m.	Creative Advocacy Not Limited by Staff or Budget
3:50-4:05 p.m.	Break
4:05-5:00 p.m.	How to Build a Productive Relationship with NINDS
5:00 p.m.	Depart NIH Campus
6:00 p.m.	No Host Dinner to continue discussions of collaborations

Reminder: Attendees are invited to the Open Session of the NINDS Advisory Council meeting beginning on September 12, at 8:00 a.m. in the Natcher Conference Center, Room E1/E2.