

Future Directions for Undiagnosed Diseases Research: The UDN and Beyond Tweets from the Workshop - March 2016

<u>User Screen Name</u>	<u>Text</u>	<u>Date Created</u>
mpsjax	RT @RareDiseases: NOW: Paul Melmeyer, AD of Policy at #NORD, speaking on advocacy 4 patients and families at #UDNConnect discussion: https://t.co/V8Jz0v58cK	3/21/2016 19:27
LtdBot	RT @RareDiseases: NOW: Paul Melmeyer, AD of Policy at #NORD, speaking on advocacy 4 patients and families at #UDNConnect discussion: https://t.co/V8Jz0v58cK	3/21/2016 19:23
RareDiseases	NOW: Paul Melmeyer, AD of Policy at #NORD, speaking on advocacy 4 patients and families at #UDNConnect discussion: https://t.co/V8Jz0v58cK	3/21/2016 19:15
SoftlySmiling	RT @BerryS730: #UDNConnect as an engine for diagnosis for #RareDisease: "What's the shortest distance to the answer?" Can it be scaled to h...	3/21/2016 19:14
DrMel_T	RT @genome_gov: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/bKXVWko3SH #UDNConn...	3/21/2016 19:10
SoftlySmiling	RT @UDNconnect: Today full agenda "Future Directions for Undiagnosed Diseases Research: The UDN and Beyond" #UDNconnect #raredisease https://t.co/sPONdwpG8Q	3/21/2016 19:10
SoftlySmiling	RT @orphanwriter: NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: https://t.co/sPONdwpG8Q #UDNConne...	3/21/2016 19:09
SoftlySmiling	RT @UDNconnect: Live streaming now at https://t.co/BDNwMgST9Q #UDNconnect #RareDisease https://t.co/DA1jve4J9V	3/21/2016 19:08
SoftlySmiling	RT @UDNconnect: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/xwG2CCZ0Bd #UDNConn...	3/21/2016 19:07
SoftlySmiling	RT @genome_gov: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/bKXVWko3SH #UDNConn...	3/21/2016 19:06
LtdBot	RT @RareDiseases: LIVE: "Future Directions for Undiagnosed Diseases Research: The UDN & Beyond" #UDNConnect webcast link below. https://t.co/DA1jve4J9V	3/21/2016 19:02
DeannaLynne1	RT @RareDiseases: LIVE: "Future Directions for Undiagnosed Diseases Research: The UDN & Beyond" #UDNConnect webcast link below. https://t.co/DA1jve4J9V	3/21/2016 18:56
RareDiseases	LIVE: "Future Directions for Undiagnosed Diseases Research: The UDN & Beyond" #UDNConnect webcast link below. https://t.co/kQT4NJ3HQC	3/21/2016 18:46
BerryS730	#UDNConnect as an engine for diagnosis for #RareDisease: "What's the shortest distance to the answer?" Can it be scaled to help more folks?	3/21/2016 18:17

BerryS730	Promoting the "virtuous cycle": bench to bedside and back again. How does this happen? And where do therapies begin? #UDNconnect	3/21/2016 17:49
DrFalsetti	RT @orphanwriter: NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: https://t.co/sPONdwpG8Q #UDNConne...	3/21/2016 15:22
BerryS730	"Finding a minimal shared reality." Finding connections to sustain new knowledge #UDNconnect	3/21/2016 14:59
DavisAngesdavis	RT @orphanwriter: NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: https://t.co/sPONdwpG8Q #UDNConne...	3/21/2016 14:42
HarvardDBMI	RT @UDNconnect: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/xwG2CCZ0Bd #UDNConn...	3/21/2016 14:37
UDNconnect	Today full agenda "Future Directions for Undiagnosed Diseases Research: The UDN and Beyond" #UDNconnect #raredisease https://t.co/dBhPxKARZF	3/21/2016 14:33
BerryS730	Who is the study of an unknown condition for, and how do we make evaluation of unknown conditions fair as well as useful?#UDNconnect	3/21/2016 14:28
UDNconnect	RT @orphanwriter: NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: https://t.co/sPONdwpG8Q #UDNConne...	3/21/2016 14:20
orphanwriter	NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: https://t.co/sPONdwpG8Q #UDNConnect	3/21/2016 14:14
colleencalshu	RT @UDNconnect: Live streaming now at https://t.co/BDNwMgST9Q #UDNconnect #RareDisease https://t.co/DA1jve4J9V	3/21/2016 14:00
LukaTheLion	RT @UDNconnect: Live streaming now at https://t.co/BDNwMgST9Q #UDNconnect #RareDisease https://t.co/DA1jve4J9V	3/21/2016 13:32
UDNconnect	Live streaming now at https://t.co/BDNwMgST9Q #UDNconnect #RareDisease https://t.co/DA1jve4J9V	3/21/2016 13:15
BerryS730	#UDNconnect planning for the future of the program. How much and when? What resources are the right amount?	3/21/2016 13:13
jgreid	RT @genome_gov: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/bKXVWko3SH #UDNConn...	3/21/2016 13:13
BerryS730	RT @UDNconnect: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/xwG2CCZ0Bd #UDNConn...	3/21/2016 13:08
UDNconnect	Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/xwG2CCZ0Bd #UDNConnect	3/21/2016 12:40
UlsterUniBiomed	RT @genome_gov: Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond https://t.co/bKXVWko3SH #UDNConn...	3/21/2016 12:37

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Watch livecast of Future Directions for Undiagnosed Diseases Research: The UDN and Beyond <https://t.co/bKXVWko3SH>
#UDNConnect #raredisease

3/21/2016 12:35

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NORD @RareDiseases · 24h

NOW: Paul Melmeyer, AD of Policy at #NORD, speaking on advocacy 4 patients and families at #UDNConnect discussion: ow.ly/ZLT0s

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NORD @RareDiseases · 1d

LIVE: "Future Directions for Undiagnosed Diseases Research: The UDN & Beyond" #UDNConnect webcast link below.

Time	Topic	Speaker
10:00	Registration and Welcome	
10:15	Introduction to the Undiagnosed Diseases Research Program	Paul Melmeyer
10:30	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
11:00	Break	
11:15	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
11:45	Break	
12:00	Lunch	
12:30	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
1:00	Break	
1:15	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
1:45	Break	
2:00	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
2:30	Break	
2:45	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
3:15	Break	
3:30	Panel: Undiagnosed Diseases Research: The UDN & Beyond	Paul Melmeyer, Susan Berry, etc.
4:00	Registration and Welcome	

Undiagnosed Diseases @UDNconnect

Today full agenda "Future Directions for Undiagnosed Diseases Research: The UDN and Beyond" #UDNconnect #raredisease

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Susan Berry @BerryS730 · 1d

#UDNConnect as an engine for diagnosis for #RareDisease: "What's the shortest distance to the answer?" Can it be scaled to help more folks?

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Susan Berry @BerryS730 · 1d

Promoting the "virtuous cycle": bench to bedside and back again. How does this happen? And where do therapies begin? #UDNconnect

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Susan Berry @BerryS730 · Mar 21

"Finding a minimal shared reality." Finding connections to sustain new knowledge #UDNconnect

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Undiagnosed Diseases @UDNconnect · Mar 21

Today full agenda "Future Directions for Undiagnosed Diseases Research: The UDN and Beyond" #UDNconnect #raredisease

7:45 a.m.	Welcome, Context, History of Program	Walter Koroshetz
8:25 a.m.	Lessons from the Undiagnosed Diseases Network	William Gahl
8:40 a.m.	Results of RFI and Goals of the Workshop	Anastasia Wise
9:00 a.m.	Experience of a Recent Patient	Brendan Lee
Current Opportunity: Six Questions (See Draft Questions for more detail.)		
9:25 a.m.	Question 1: Intensive Clinical Evaluation	Framer: Laura Mamounas UDN Perspective: Calum MacLae Outside Expert Perspective: Cynthia Powell Moderator/Summarizer: Jonathan Mink
10:05 a.m.	Break	
10:20 a.m.	Question 2: Transitions of Care	Framer: Jyoti Gupta UDN Perspective: Christine Eng Outside Expert Perspective: Susan Berry Moderator/Summarizer: Darcy Kreuger
11:00 a.m.	Question 3: Patient and Family Partnership	Framer: John Mulvihill UDN Perspective: Vandana Shashi Outside Expert Perspective: Donna Appell Moderator/Summarizer: Judith Hall
11:40 a.m.	Question 4: Training, Sharing and Collaboration	Framer: Carson Loomis UDN Perspective: Rachel Ramoni Outside Expert Perspective: Ronald Cohn Moderator/Summarizer: Marishka Brown
12:20 p.m.	Lunch	
1:20 p.m.	Question 5: The Virguous Cycle and Integrating Data	Framer: Donna Krasnewich UDN Perspective: David Koeller Outside Expert Perspective: Stephen Prescott Moderator/Summarizer: Jonathan Mink
2:00 p.m.	Question 6: Moving the UDN Forward	Framer: David Eckstein UDN Perspective: Rizwan Hamid Outside Expert Perspective: Bruce Korf Moderator/Summarizer: Haren Scheuner
3:00 p.m.	Break	
Panel of Experts' Prespectives (5-minute comments each, then 30 minutes discussion)		
3:15 p.m.	Topic: ASHG/ACMG	Panelist: David Flannery
	Topic: Specialist	Panelist: Irene Haumence

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Susan Berry @BerryS730 · Mar 21

Who is the study of an unknown condition for, and how do we make evaluation of unknown conditions fair as well as useful?#UDNconnect

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Mary Dunkle @orphanwriter · Mar 21

NORD speaking on behalf of #undiagnosed #raredisease patients today. View live webcast: genome.gov/27564304 #UDNConnect