

## Steering Committee Meeting Agenda November 3, 2016 – November 4, 2016

Washington Marriott Wardman Park  
2660 Woodley Road NW Washington District of Columbia, 20008  
Exhibit Hall B North - Washington 4 Conference Room

Day 1 – November 3, 2016		
Time	Topic	Presenter/Moderator
8:00 AM-7:00 PM	<b>CCRRD</b>	Peter Merkel, MD, MPH
7:30 PM	<b>PI Dinner</b> at Petit Plats – 2653 Connecticut Avenue, NW (across the street from hotel). Group meeting in lobby at 7:15 pm after CCRRD wine and cheese reception to walk over to restaurant. <b>PM Dinner</b> at Harry's Pub (located in hotel). Meet at restaurant at 7:30 pm.	

Day 2 – November 4, 2016			
Time	Min	Topic	Presenter/Moderator
<8:00 AM		<b>Registration</b> , Located at Exhibit Hall B North	
8:00 AM	60	<b>Sub-Committees Breakout Session and Location:</b> <ul style="list-style-type: none"> <li>• Strategic Planning Committee/NIH Awareness Task Force at Exhibit Hall B North - Washington 5</li> <li>• Training Committee at Exhibit Hall B North - Washington 6</li> </ul>	Peter Merkel, MD, MPH/ Bruce Trapnell, MS, MD Michael Shy, MD
9:00 AM	15	<b>Break</b>	
9:15 AM	5	<b>Welcome and Introductions</b> <ul style="list-style-type: none"> <li>• Agenda &amp; Review of October 18, 2016 Meeting Minutes</li> </ul>	Michael Benatar, MD, PhD
9:20 AM	15	<b>Office of Rare Diseases Research (ORDR) Report</b>	Petra Kaufmann, MD
9:35 AM	5	<b>Office of Rare Diseases Research (ORDR) Updates</b>	Rashmi Gopal-Srivastava, PhD
9:40 AM	10	<b>NCATS SMART IRB Model</b>	Michelle Culp, MPH
9:50 AM	10	<b>CTSA Collaborative Innovation Awards Program</b>	P.J. Brooks, PhD
10:00 AM	5	<b>CPAG Report</b>	Chuck Mohan
10:05 AM	10	<b>Data Management &amp; Coordinating Center (DMCC) Report</b>	Jeffrey Krischer, PhD
10:15 AM	15	<b>Break</b>	
10:30 AM	5	<b>Central IRB Impact, Introduction</b>	Julie Martin, RN, MEd, CCRP
10:35 AM	10	IRB Representative (UCDC)	James McNerney, JD, CIP, RAC
10:45 AM	10	Site Representative (UCDC)	Kara Simpson, MS
10:55 AM	10	Consortium Representative (CEGIR)	Marc Rothenberg, MD, PhD
11:05 AM	10	SMART IRB Model Representative	Nichelle Cobb, PhD
11:15 AM	20	<b>Discussion/Questions</b>	
11:35 AM	5	<b>Scientific Achievements Introduction</b>	Jeffrey Krischer, PhD
11:40 AM	10	<ul style="list-style-type: none"> <li>• VCRC Clinical Trial Results</li> </ul>	Carol Langford, MD, MHS
11:50 AM	10	<ul style="list-style-type: none"> <li>• LDN Clinical Trial Results</li> </ul>	Chester Whitley, PhD, MD
12:00 PM	10	<b>Discussion/Questions</b>	
12:10 PM	60	<b>Lunch</b> , Located at Plaza Foyer	
1:10 PM	5	<b>Intellectual Property Claims, Introduction</b>	Michael Benatar, MD, PhD
1:15 PM	10	Industry Representative (Shire Pharmaceuticals, Inc.)	David Whiteman, MD, FAAP, FACMGG
1:25 PM	10	Consortium Representative (Lysosomal Disease Network)	Chester Whitley, PhD, MD
1:35 PM	10	PAG Representative (Friedreich's Ataxia Research Alliance)	Ronald Bartek



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### Day 2 – November 4, 2016

Time	Min	Topic	Presenter/Moderator
1:45 PM	20	<b>Discussion/Questions</b>	Michael Benatar, MD, PhD
2:05 PM	5	<b>Trainee Presentations Introduction</b>	Michael Shy, MD
2:10 PM	10	<ul style="list-style-type: none"> <li>• Bioanalytical Validation of a Near-Patient Blood Ammonia Meter</li> </ul>	Omar Ayyub, PhD
2:20 PM	10	<b>Discussion/Questions</b>	Michael Shy, MD
2:30 PM	10	<b>Committee Reports (5 min each)</b> <ul style="list-style-type: none"> <li>• Strategic Planning Committee</li> <li>• Training Committee</li> </ul>	Peter Merkel, MD, MPH Michael Shy, MD
2:40 PM	5	<b>New Business</b>	Michael Benatar, MD, PhD
2:45 PM		<b>Adjourn</b>	Michael Benatar, MD, PhD