**RDCRN CERTIFICATE PROGRAM IN-PERSON MEETING SEPTEMBER 2015: NORD Headquarters in the Carnegie Building 1779 Massachusetts Ave, Choate Room 1st floor**

**SEPTEMBER 29**

9:30 **Arrival/Check** in at the Choate Room of the NORD Headquarters (1779 Massachusetts Avenue)

10:00 **Welcome** by Dr. Marshall Summar, Dr. Mary Ottolini, and Dr. Debra Regier

10:30 **Participant Introductions:**  “1 minute elevator description of your research”

11:00 **Welcome to the World of Rare Disease Research. NCATS is Glad You’re Here!**Dr. Chris Austin (NCATS Director)

12:00 **Lunch** (In Choate Room)

1:00 **Role of the FDA in Facilitating Rare Disease Clinical Trials and the Elements Needed to Succeed.** Devanand Jillapalli, MD ( Neurology)

2:30 **Unique Skill Sets in Rare Disease Clinical Research: Presentation and Group Discussion**

Biostatistics in Small Populations, Dr. Bob McCarter

Creating budgets and using the EMR to “recruit” patients for your trial, Dr. Pablo Cure

3:45 **Cookie Break**

4:00 **Patient-Centered Outcomes Research Institute: How They Can Help Us Succeed in Rare Disease Research.** Dr. Danielle Whicher, Clinical Effectiveness Research Program Officer

**SEPTEMBER 30**9am: **National Organization for Rare Disorders,** Paul Melmeyer

10 am: **Adult Education and learnrd.com** , Dr. Mary Ottolini, Jeff Sestokas, Dr. Debra Regier
website portal (tutorial in accessing what you need when you need it). Bring a computer, phone, iPad.

11 am**: Leveraging Family Groups for Advocacy, Study Support, and Clinical Trial Participants**

 Jana Monaco, parent and advocate for rare disease research and funding.

12**: Lunch**

**Capitol Hill Field Trip**2:00: Meet at Rayburn 2266
2:30: Capitol Tour
4:00: Meet with Drs. Summar, Summar, and Flamm: A conversation with Health Care Policy experts to understand the role of Capitol Hill on YOUR research.