



# ADVANCING RARE DISEASES RESEARCH THROUGH NETWORKS AND COLLABORATION

July 16, 2009

NIH Natcher Conference Center • Bethesda, MD

## AGENDA

- Purpose:**
1. Provide unique advances in RDCRN
  2. Highlight successful collaborations to improve rare diseases research
  3. Highlight the involvement and essential role of patient advocacy groups to facilitate Research and accrual of patients
  4. Discuss procedures to apply standards across research consortia and research network.
- 7:30 a.m. Registration and Poster Set-up**  
Continental Breakfast
- 8:00 a.m. Welcome**  
Office of Rare Diseases Research, NIH  
National Center for Research Resources, NIH
- 8:15 a.m. Keynote**
- 9:00 a.m. Challenges and Opportunities in Rare Disease Research**
- 9:20 a.m. Training Professionals in Rare Disease Research Panel**
- 10:00 a.m. Break**
- 10:30 a.m. Participant Recruitment, Outreach, and Dissemination Panel**
- 11:30 a.m. LUNCH (ON YOUR OWN) AND POSTER SESSION**
- 1:00 p.m. Strategies in Collaborations and Forming Effective Teams, Networks**  
Moderator and Panel
- 1:45 p.m. Sharing across Diseases**  
Moderator and Panel
- 2:30 p.m. Break**
- 2:45 p.m. Basic-Clinical Translation**  
Moderator and Panel
- 3:30 p.m. Clinical-Practice Translation**  
Moderator and Panel
- 4:15 p.m. Wrap Up**  
National Human Genome Research Institute
- 4:30 p.m. ADJOURN**  
Office of Rare Diseases Research, NIH