Rare Diseases Clinical Research Network (RDCRN)

A MODEL FOR COLLABORATIVE RARE DISEASES RESEARCH WITH PATIENT ADVOCACY GROUPS AS PARTNERS
RDCRN: Background Information

- Established in 2003 and expanded in 2009
- 3rd cycle renewal in 2014:
  - a Network of 22 distinct multi-site Clinical Research Consortia (U54 - no more than $1.25M Total Cost/year)
  - Each Consortium studies at least three related rare diseases
  - A central Data Management and Coordinating Center (DMCC)
  - Involves Patient Advocacy Groups - CPAG
  - 10 NIH ICs as research partners
About RDCRN

- Each consortium conducts at least two multi-site clinical studies, has a training program, and pilot project program.
- Collectively, the RDCRN is studying 200 rare diseases in natural history and clinical trials at 240 clinical sites located in the US and in 14 countries.
- There are more than 90 active protocols.
- 29,000 patients have enrolled in clinical studies.
- There have been 174 trainees.
- There are 2,290 collaborative consortium members.
- There are 98 PAGs as research partners.

http://rarediseasesnetwork.epi.usf.edu/