Rare Disease Day Celebration
Saturday February 14, 2015
McKenna Hall - 2:00pm-6:00pm

2:00-2:10  
Introductions and Welcome

2:15-2:45  
Rare Disease Experimental Therapies Forum
Dr. Elizabeth Berry-Kravis, MD, PhD
From Phase 1 to Phase 2 clinical trials

2:30-2:45  
Discussion Panel
Dr. Shaun Lee, PhD, Dr. Kasturi Haldar, PhD, and other faculty; Harry Koujaian, and ND students

2:50-3:35  
Rare Disease Patient Care in Local Community
Dr. Carol Luzzi, Developmental Pediatrician, Memorial Developmental Pediatrics, South Bend, IN
Karen Quandt RN, MSN Vice President Intl Niemann Pick Disease Alliance

3:20-3:35  
Discussion Panel
Local practitioners, families and students

3:40-4:10  
Living with a Rare Disease
Bernard Gray ’14, graduate student, mathematics
Common Variable Immunodeficiency Disease

3:55-4:10  
Discussion panel
RareND Club Co-Presidents Mia McReynolds and Danny McKee, Jacqlyn Riemersma and students

4:15-4:45  
Poster session Notre Dame undergraduate & graduate students

4:45-5:15  
Rare Disease Patient Portal
Daniel McCormack ’15, Computer Science College of Engineering
From Data to Diagnosis of Rare Diseases

5:00-5:15  
Discussion Panel
Waldo Mikels-Carrasco, Michiana Health Information Network, Daniel McCormack ’15, Bradley Stalcup ’15 and Robert Power, ESTEEM

5:15-5:40  
Rare ND Club
Rare Disease Quiz and Review

5:45  
Rare Disease Fight Song