Rare Disease Day Celebration
Saturday, February 27, 2016 Jordan Hall 105
9am-5.30pm

9:00-9:15am  Welcome, University of Notre Dame Glee Club
             *Rare Disease Fight Song*
             RHE, RareND and Rare Disease Education and Awareness
             Kasturi Haldar, PhD

9:15-9:35am  *Rare Genetic Disorders in the Plains Community*
             Chris Roberson, Director, Compliance and Community Programs, Indiana Hemophilia & Thrombosis Center, Inc. (IHTC)

9:35-9:55am  *Community Health Clinic, Caring for NKH and Rare Disorders in Plain Community*
             Zineb Ammous, MD, Clinical Geneticist

10:00-10:45am  *NKH Patient Families Panel*
                Patient families, Clinicians, and ND Students

10:45-11:15am  *Coffee Break and Poster Session*

11:15-11:45am  *Niemann Pick Type C Discussion Panel*
                Patient families, Clinicians, and ND students

11:45-12:05am  *Pompe Disease and the Notre Dame Experience*
                John Crowley, Chairman and CEO, Amicus Therapeutics

12:05-1:00pm  *Lunch*

1:00-1:20pm  *The Ganey Project, Caring for Rare Diseases in Primary Care*
             MaryAlice, Reid, MD, Barb Calhoun, RN, PNP, and Kasturi Haldar, PhD
             *Neurofibromatosis Type 1*- Nicole Sevison, RN; Madeline Zupan, ND ’16

             *Other Rare Diseases in Our Local Community*
             *Morquio Diseases*- Nicole Ingle; Roland Rebuyon, ND ’16
             *Glut1TDS*- Cindy and Jyl Riemersma; Jacqlyn Riemersma ND ‘16
             *Idiopathic Hypersomnia*: Maggie Mendez and ND students
3:15-3:45pm  Break

3:45-4:45pm  Sprintfzen Goldberg Syndrome- Melissa Kern, ND students
              Rett Syndrome- David Faverty, Matthew Krutchen, ND’16
              Primary Lateral Sclerosis- Heidi Johnson, and ND students
              Fragile X- Sarah Snyder and ND students

4:45-5:30pm  Community Discussion panel and wrap-up