World Rare Disease Day Celebration

February 15, 2014

9:00 am  Welcome & Dedication for Tylor White-Richardson & Riley Smith
          Kasturi Haldar, PhD

9:15 am   Rare Diseases: New Targeted Therapies
          Elizabeth Berry-Kravis, MD, PhD

9:45 am   Experimental Drugs Forum
          Elizabeth Berry-Kravis, MD, PhD & Harry Koujaian

10:45 am  Amyloidosis Support Groups Inc.
          Muriel Finkel

11:00 am  Patient & Family Panel: Living with a Rare Disease
          Koujaian family, Mroczek family, Riemersma family & other
          Patients/families

12:00 pm  Lunch

1:00 pm   Lysosomal Storage Diseases Research
          M. Suhail Alam, PhD, Olaf Wiest, PhD, Shaun Lee, PhD, Anthony Serianni, PhD

2:00 pm   Developing Treatments for Rare Cancers
          Basar Bilgicer, PhD, Cassie Buchheit, Laurie Littlepage, PhD

3:00 pm   Poster session and coffee break

3:45 pm   Health Insurance Coverage and the Affordable Care Act
          Mike Hamerlik, CEO, WPS Health Insurance
          Coley Mroczek

4:30 pm   Rare Health Exchange Student Panel
          Bianca Fox, Yuan Gao (ND ESTEEM Masters Program)
          Nitesh Chawla, PhD, ND Students and Harry Koujaian
          Barbara Calhoun, MSN, RN, PNP

5:30 pm   Rare Disease Quiz
          “Rare ND” student club

5:45 pm   Closing remarks & Rare Disease Fight Song