RARE DISEASE ON MAIN STREET

Celebrating International Rare Disease Day
*Individuals Living with Lysosomal Disease*

Monday March 2, 2015

Price Center/Block Research Pavilion • LeFrak Auditorium

2:00 – 2:15 PM  Introductory Remarks by Steven Walkley

2:15 – 3:00 PM  Life Story Panel

  Interviewers:  Dr. Robert Marion & Dr. Frederick Kaskel
  Panelists:  Suzanne Krupskas (Gaucher)
              Alena Galan (MPS VI)
              Gail Graf (Fabry)
              Laura Krummenacker (Cystinosis)

3:00 – 3:30 PM  Advocacy Panel

  Interviewer:  Dr. Paul Levy
  Panelists:  Jill Wood (parent representing MPS IIIC)
              Phil and Andrea Marella (parents representing Niemann-Pick type C)

Forchheimer Main Street

3:30 – 5:00 PM  Wine & Cheese Reception

Featuring selections from Levi Gershkowitz’ “Living in the Light”™ project, and Genzyme Corporation’s “Expressions of Hope” program. There will also be a live performance by Alena Galan.

http://einstein.yu.edu/centers/iddrc/

“Nature is nowhere accustomed more openly to display her secret mysteries than in cases where she shows traces of her workings apart from the beaten path; nor is there any better way to advance the proper practice of medicine than to give our minds to the discovery of the usual law of Nature by careful investigation of cases of rare forms of disease.” –William Harvey 1657