RARE DISEASE ON MAIN STREET

Celebrating International Rare Disease Day
Individuals Living with Lysosomal Disease
TUESDAY, FEBRUARY 28, 2017

Price Center/Block Research Pavilion • LeFrak Auditorium

2:00–2:15 PM Introductory remarks on rare disease research at Einstein/ Montefiore.
Steven Walkley, D.V.M., Ph.D., Director, Rose F. Kennedy Intellectual and Developmental Disabilities Research Center

2:15–3:00 PM Photographic and narrative presentation (http://www.frompatienttoperson.com/); Q&A. Levi Gershkowitz, Founder & Director of Living in the Light™

3:00–4:00 PM Rare Disease Advocacy Panel Discussion:

PANELISTS:
Robert Marion, M.D. – Professor, Departments of Pediatrics (Pediatric Genetic Medicine) and Obstetrics & Gynecology and Women’s Health (Reproductive & Medical Genetics); former Chief, Division of Genetics, Department of Pediatrics, Einstein & Montefiore.
Sheila Kambin – Chair, International 22q11.2 Foundation, Inc.; mother of Aidan, age 12, who has 22q11.2 deletion syndrome.
Philip Marella – Founder, Dana’s Angels Research Trust (DART) and Support of Accelerated Research for Niemann-Pick type C disease (SOAR-NPC); father of two children with Niemann-Pick type C disease, Dana (deceased) and Andrew, age 17.
Rebecca Oberman, Ph.D. – Executive Director, ML4 Foundation.

Forchheimer Main Street
4:00–5:30 PM Scientific Poster Session & Reception

Sponsored by the Rose F. Kennedy Intellectual and Developmental Disabilities Research Center, the division of genetics, the department of pediatrics and the Molecular and Cellular Foundations of Medicine course.