Thursday, June 30th, 2016
12:00 pm – 5:00 pm

11:30 – Registration Opens & Networking Lunch

12:30 – Welcome – Master of Ceremonies
   • Klane White, M.D., Pediatric Orthopedic Surgeon, Seattle Children’s Hospital

12:45 – Keynote Addresses
   • James Hendricks, Ph.D – President, Seattle Children’s Hospital Research Institute
   • Senator Patty Murray (D-WA) (video remarks)
   • Representative Suzan DelBene (D-WA1)

1:30 – Overview of the EveryLife Foundation for Rare Diseases
   • Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases

1:45 – Panel 1: Why Public Policy Matters/History of Rare Disease Policy
   • Dean Suhr – President and Founder, MLD Foundation, Member, RUSP Roundtable Initiative
   • Leslie Fox – Healthcare Policy and Advocacy Director, Johnson & Johnson

2:45 – Dessert Break

3:00 – Overview of In-District Lobby Days
   • Vignesh Ganapathy – Manager of Advocacy and Government Relations, EveryLife Foundation for Rare Diseases

3:15 – Panel 2: How to Advocate for the Rare Disease Community
• 21st Century Cures Act/OPEN ACT: Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases
• Appropriations specific to NIH/FDA funding: Max Bronstein, Senior Director, Advocacy & Science Policy, EveryLife Foundation for Rare Diseases

4:00 – Practice Legislative Meetings
5:00 – Adjourn

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