Tuesday, June 28, 2016
10:00am – 3:00pm

10:00am  Welcome: Moderator
Jack Whelan, Patient Advocate

10:10am  Overview of the EveryLife Foundation for Rare Diseases
Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases

10:20am  Keynote Address on the Impact of Public Policy on Patients
Michael Astrue, Former Social Security Administration Commissioner

10:50am  Panel Discussion: Building and Maintaining Relationships with Elected Officials and Staff
- Robert Coughlin, President and CEO, Massachusetts Biotechnology Council
- Lisa Schill, Vice President, RASopathies Network USA
- Nicole Caravella, District Coordinator, U.S. Representative Joseph Kennedy III (D-MA)

11:40am  Importance of Robust Funding for the National Institutes of Health (NIH) and Food and Drug Administration (FDA)
Tim Leshan, Vice President of Government Relations, Northeastern University

12:10pm  Video Message from U.S. Representative Gus Bilirakis (R-FL) on the OPEN ACT

12:15pm  Potential Benefits of the 21st Century Cures Act and the OPEN ACT
Dr. Emil Kakkis, Founder and President, EveryLife Foundation for Rare Diseases

@RareAdvocates
www.RareAdvocates.org
12:40pm  Networking Lunch

1:40pm  Video Message from House Energy and Commerce Committee Chair Fred Upton (R-MI)

1:45pm  Overview of In-District Lobby Days
Stephanie Fischer, Senior Director of Patient Engagement and Communications, EveryLife Foundation for Rare Diseases

2:00pm  Best Practices for Advocating for Issues in a Digital World
Amy O’Connor, Senior Director, Digital and Social Media Communications, Eli Lilly and Company

2:50pm  Closing Remarks: Jack Whelan

Thank you to our sponsors and advocacy partners!

@RareAdvocates
www.RareAdvocates.org