



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



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- 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**

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