



## Legislative Conference Agenda

*Tuesday, February 25, 2014*

*National Press Club, Washington DC*

8:15 - 9:00 am ***Breakfast & Registration***

9:00 - 9:15 am **Welcome - Overview of the Day**

Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases

Conference Moderator: Dean Suhr, President and Founder, MLD Foundation

### **State Level Organization & Advocacy Efforts**

9:15 - 10:00 am **Patient Organization Best Practices**

Charles A Mohan, Jr., CEO/ED, United Mitochondrial Disease Foundation

Mary Cobb, New Jersey RARE

Blair Van Brunt, President, Shwachman-Diamond Syndrome Foundation

10:00 - 10:55 am **Affordable Care Act Implementation**

Joel White, President & Founder, Horizon Government Affairs

Tracy Baroni-Allmon, Executive Director Health Policy, Novartis

10:55 - 11:40 am **Newborn Screening**

Emil Wigode, Director of Federal Affairs, March of Dimes

Natasha Bonhomme, Director, Baby's First Tests

Anna Grantham, Manager of Newborn Screening, Hunter's Hope Foundation

11:40 - 12:15 pm ***Lunch Break***

12:15 - 12:55 pm **Key Note Address**

**Art Estopinan, Parent Advocate, Mitochondrial Disease**

**Chief of Staff, Office of Representative Ros-Lehtinen (R-FL)**

12:55 - 1:25 pm **2014 Midterm Elections & Rare Disease Legislation**

Dem: Rob Houton, Principal of Whitmer & Worrall, LLC

GOP: Nick Manetto, Director, FaegreBD Consulting



**Who Influences Legislation?**

1:25 - 2:05 pm

**Industry Stakeholders**

*TBD, Pharmaceutical Research and Manufacturers of America (PhRMA)*

Howard Moon, Executive Director U.S. Government Affairs, **Amgen**

Jeanne Haggerty, Senior Director Federal Government Relations, **BIO**

Samantha Ventimiglia, VP Government Affairs & Public Policy, **Vertex**

Kelly Slone, VP Life Science Policy, **National Venture Capital Association**

Todd Gillenwater, Interim President & CEO, **CHI-California Healthcare Institute**

2:05 - 3:00 pm

**Patient Organization Stakeholders**

Miriam O'Day, **National Organization for Rare Disorders (NORD)**

Natasha Bonhomme, Vice President of Strategic Development, **Genetic Alliance**

Nicole Boice, President, **Global Genes|RARE Project**

Emil Kakkis MD PhD, President, **EveryLife Foundation for Rare Diseases**

Stephanie Krenrich, Sr. Mgr. Government Affairs, **Cystic Fibrosis Foundation**

Eric Gascho, Assistant VP of Government Affairs, **National Health Council**

Jeff Allen PhD, Executive Director, **Friends of Cancer Research**

Cecilia Arradaza, Managing Director Communications & Policy, **FasterCures**

3:00 - 3:15 pm

***Break***

3:15 - 3:45 pm

**Legislation Breakout Sessions**

MODDERN Cures Act

Patients Access to Treatment Act

Undiagnosed Disease Registry

3:45 - 4:30 pm

**Overview of Lobby Day Schedules**

Kevin Schultze, Vice President Congressional Relations, SoapBox Consulting

4:30 pm

**END OF CONFERENCE: THANK YOU FOR COMING**

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