

IN-DISTRICT

LOBBY DAYS



RARE DISEASE LEGISLATIVE ADVOCATES

MIDWEST CONFERENCE

Hosted by



Presented by



Thursday, June 30th, 2016

Agenda

- 10:00 am** **Welcome: Moderator:** Steve Smith, CEO and Management Consultant, SteveSmithPlans LLC
- 10:05 am** **Overview of the EveryLife Foundation for Rare Diseases**
Carol Kennedy, CFRE, Chief Development Officer, EveryLife Foundation for Rare Diseases
- 10:20 am** **Messages from Members of Congress**
Cindy Wellwood – Burke, Director of Constituent Services and Advocacy, Senator Mark Kirk (R-IL)
- 10:30 am** **Why Public Policy Should Be a Top Priority for Rare Disease Patients**
Moderator: Marilyn Vetter, Vice President, Government and Public Affairs, Horizon Pharma
- Dorelia Rivera, Parent Advocate
 - Tracy VanHoutan, President, Noah's Hope, and Vice President, Batten Disease Support and Research Association
 - Clyde W. Yancy, MD, MSc, MACC, FAHA, MACP, Vice Dean, Diversity and Inclusion, Northwestern University, Feinberg School of Medicine
- 11:30 am** **Networking Lunch**



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