

IN-DISTRICT  
LOBBY DAYS



RARE DISEASE LEGISLATIVE ADVOCATES

# WEST COAST CONFERENCE

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



*James Hendricks, Ph.D, President  
Seattle Children's Research Institute*



*Senator Patty Murray  
U.S. Senator*



*Rep. Suzan DelBene  
U.S. Representative (WA-1)*

## **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**

- 21<sup>st</sup> 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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