



Join the Rare Disease California Caucus, led by Assemblymember Bonta (D-Oakland) and Assemblymember Maienschein (R-San Diego), for a lunch briefing on rare disease issues.

RARE DISEASE 101 INFORMATIONAL BRIEFING

Wednesday, April 11, 2018

12:00 PM - 1:00 PM

State Capitol, Room 3191

Lunch will be served

AGENDA

- Welcome and Purpose
- Overview of Rare Diseases: What is Rare?
 - Angela Ramirez Holmes, President, California Action Link for Rare Diseases (CAL RARE)
- Patient Perspectives
 - Andrew Holmes, 13 year old with brain arteriovenous malformation
 - Rachele Dixon, President, HSN1E Society
- Innovation in California: Whole Genome Sequencing
 - UC Davis Genome Center
 - Kathleen Lynch, Senior Director, Global Government Affairs and Public Policy, Illumina
- Budget Proposal by Caucus Chairs for Clinical Pilot Project
- Public Comment

Please RSVP to Alma Barreras at Alma.Barreras@asm.ca.gov or 916-319-2018.

