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
  - Rachelle Dixon, President, HSAN1E 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.