



Chairs: Assemblymembers Rob Bonta, Brian Maienschein, Marie Waldron

**Informational Hearing
Subject: Rare Research
Tuesday, August 27, 2019
11:00am-12:00pm
State Capitol, Room 127**

Lunch will be served in Room 125 following hearing

AGENDA

I. Welcome

II. Overview

- i. Angela Ramirez Holmes, Founder/President, California Action Link for Rare Diseases (CAL RARE)

III. Spotlight on Amyloidosis

- i. Dr. Martin Cadeiras, Cardiovascular Medicine, UC Davis
- ii. Len Strickland, Patient Perspective on Living with Rare Disease

IV. Rare Disease Caucus at Work

- i. Update on Whole Genome Sequencing Pilot Project/Project Baby Bear: Dr. Lauge Farnaes, Rady Children's Institute for Genomic Medicine
- ii. Sickle Cell Disease 2019-20 California Budget Appropriation: Assemblymember Mike Gipson, Rare Disease Caucus Member

V. Innovation in Rare Disease, A Look Ahead

- i. The Innovation of Digital Medicine: Bruce Carroll, Vice President of Healthcare Policy, Proteus Digital Health

VI. Public Comment

VII. Closing Remarks