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