



# YEAR IN REVIEW

## 2019!

CAL RARE is dedicated to improving the lives of rare disease patients in California. We are a coalition of rare disease stakeholders raising awareness among the general public and decision makers regarding rare diseases. We want to bring recognition to the issues rare disease patients face and work to ensure access to physicians, treatments, and social services.



The Rare Disease California Caucus is a bipartisan Caucus led by Assemblymember Rob Bonta (D-Oakland), Assemblymember Brian Maienschein (D-San Diego), and Assembly Minority Leader Marie Waldron (R-Escondido).

### GOALS:

- Bring public and legislative awareness
- Ensure patients have a voice in shaping policy
- Educate legislators and staff about rare disease policy issues
- Opportunity for legislature to engage with rare disease community (patients, academia, hospitals, biopharmaceutical industry, government agencies)

*25% of the State Legislature has joined the Caucus!*

- ✓ \$15 million in CA Budget for Sickle Cell Disease Centers of Excellence
- ✓ Rare Disease Caucus Hearing: Rare Research
- ✓ Joint Rare Disease Caucus Hearing with Assembly Select Committee on Biotechnology: Project Baby Bear Interim Report
- ✓ International Pain Foundation Top 100 Social Media Advocates for Rare Disease 2019
- ✓ Rare Disease Awareness Night at Golden State Warriors
- ✓ 1st Annual Member Reception at Global Genes Patient Advocacy Summit
- ✓ Featured Speakers at Rare Disease California Caucus briefings, Ultragenyx Family Day, Global Genes Patient Advocacy Summit, Orphan Drugs and Rare Diseases Conference, BridgeBio Patient Day, Disorder: Rare Disease Film Festival, CA Newborn Screening Stakeholder Meeting, The Aneurysm and AVM Foundation (TAAF) Patient Group
- ✓ Rare Disease Day Advocacy and Lunch Program at the State Capitol
- ✓ Rare Meetup at Disorder: Rare Disease Film Festival
- ✓ Expanded Board of Directors
- ✓ Rare Partnerships: Rare Disease Film Festival, International Pain Foundation, EveryLife Foundation for Rare Diseases, Global Genes Foundation Alliance, Rare and Undiagnosed Network



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