



## **RARE DISEASE CAUCUS ANNOUNCES \$2 MILLION PILOT PROJECT IN STATE BUDGET**

### **FOR IMMEDIATE RELEASE**

**July 28, 2018**

**Sacramento, CA:** The bipartisan Rare Disease Caucus announced today that the State Budget signed by Governor Jerry Brown includes \$2 million to establish a California clinical pilot project to test a minimum of 100 Medi-Cal neonatal and other pediatric patients with undiagnosed diseases using clinical Whole Genome Sequencing. Whole genome sequencing is the process of determining the complete DNA sequence of a patient's genome at a single time.

"California is the home to this innovation. This pilot project will advance precision medicine in California by demonstrating the cost-effective availability of technology to identify difficult to diagnose genetic conditions and more efficiently guide treatments for Medi-Cal patients," said Assemblymember Brian Maienschein (R-San Diego), co-chair of the Rare Disease Caucus.

The rare and undiagnosed genetic disease population is large. There are over 7,000 identified rare diseases. Most patients will go 5-7 years without a diagnosis. Science based projections indicate there are likely in excess of 150,000 rare, undiagnosed, genetic diseases affecting Medi-Cal pediatric patients.

"The toll on families of sick children is enormous. Timely diagnosis and treatment will save lives," said Assemblymember Rob Bonta (D-Oakland), co-chair of the Rare Disease Caucus. "This pilot project will give us the data we need to evaluate how to best help rare disease patients in California."

"The first briefing of the Rare Disease Caucus was on this topic and we are pleased to see such immediate results to save the lives of California children. We are grateful to our Caucus Champions, to the State Legislature, and to Governor Brown for their urgent action," said Angela Ramirez Holmes, parent advocate and President of Cal Rare, the non-profit organization helping to coordinate the Caucus.

The State Department of Health Care Services will provide the \$2 million one-time money as a grant to a state non-profit organization for the execution of the pilot project and to provide updates to the Department and to the Legislature.

*The bipartisan Rare Disease California Caucus is led by Assemblymember and Health Committee Member Rob Bonta (D-Oakland) and Assemblymember and Health Committee Vice-Chair Brian Maienschein (R-San Diego) to promote awareness of rare disease issues. The Caucus membership currently has 22 Assemblymembers and 6 Senators.*

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