

February 16, 2010

The Honorable Ted Lieu  
Chair, Assembly Rules Committee  
California State Assembly  
State Capitol, Room 3016  
Sacramento, CA 95814

**RE: Assembly Concurrent Resolution 117 – SUPPORT AS PROPOSED  
TO BE AMENDED**

Dear Assembly Member Lieu:

On behalf of the California Healthcare Institute (CHI), whose more than 250 members include our state's premier life sciences companies and academic research institutions, I am writing in support of ACR 117, a resolution that recognizes rare disease day in California on February 28, 2010.

Rare diseases are those which affect less than 200,000 Americans. While the total number of patients affected by any rare disease may be small, collectively 30 million Americans suffer from a rare disease, or about 10 percent of the population. In California alone, that equals nearly four million patients who suffer from a rare disease.

There are over 7,000 known rare diseases and conditions. While some rare diseases are well known – such as Lou Gehrig's Disease and Huntington's Disease – many others are far more obscure. Over 340 orphan drugs have been approved to treat myriad rare diseases. However, for 15 million patients in the United States suffering from a rare disease or condition, there are no treatment options.

CHI is sponsoring ACR 117 to shine a light on the biomedical research and innovation taking place in California aimed at developing treatments and cures for rare diseases. Our member companies are working tirelessly to expand the understanding of rare diseases and to give hope to patients suffering from rare diseases that currently have no treatment options.

We encourage the legislature to proclaim February 28, 2010 as "Rare Disease Day" in California, in conjunction with other rare disease day observations in the United States and around the world.

Sincerely,

A handwritten signature in black ink, appearing to read "Sandra Pizarro". The signature is fluid and cursive, with a long horizontal stroke at the end.

Sandra Pizarro  
Vice President – State Government Affairs

cc: Chair & Members, Assembly Rules Committee  
Anna McCabe, Consultant, Assembly Rules Committee  
Assembly Republican Caucus