

Date of Hearing: February 25, 2021

ASSEMBLY COMMITTEE ON RULES
Ken Cooley, Chair
HR 25 (Bonta) – As Introduced February 19, 2021

SUBJECT: Rare Disease Day.

SUMMARY: Proclaims February 28, 2021, as Rare Disease Day in California. Specifically, **this resolution** makes the following legislative findings:

- 1) There are nearly 7,000 diseases and conditions that are considered rare, each affecting fewer than 200,000 Americans, according to the National Institutes of Health.
- 2) While each of these diseases may affect a small number of people, rare diseases as a group affect almost 30 million Americans and many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected.
- 3) While more than 600 drugs and biologics have been approved for the treatment of rare diseases, according to the United States Food and Drug Administration, millions of Americans still have rare diseases for which there is no approved treatment.
- 4) Individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services.
- 5) While the public is familiar with some rare diseases, such as “Lou Gehrig’s disease,” and are sympathetic to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments.
- 6) Millions of Californians are among those affected by rare diseases because nearly one in 10 Americans has a rare disease.

FISCAL EFFECT: None

REGISTERED SUPPORT / OPPOSITION:

Support

California Action Link for Rare Diseases (Cal Rare)

Opposition

None on file

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