



April 22, 2020

The Honorable Susan Talamantes Eggman
State Capitol
P.O. Box 942849
Sacramento, CA 94249-0013

Re: NORD Support for AB 2283 to create California's Rare Disease Ombudsperson and Rare Disease Advisory Council

Dear Assemblymember Eggman,

On behalf of the 1-in-10 individuals in California with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for introducing Assembly Bill 2283, which would create a Rare Disease Ombudsperson and Rare Disease Advisory Council (RDAC) in California. NORD is pleased to support AB 2283, which is much needed legislation that would help to give a voice to the rare disease community within California's government.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

Rare diseases are present across a broad spectrum of medical conditions. For example, there are more than 500 types of rare cancers and all forms of pediatric cancer are rare. For patients suffering from these and numerous other rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well-understood, with most not receiving sufficient attention or funding for research.

Creating an RDAC and a Rare Disease Ombudsperson will give rare disease patients a unified voice in California's state government. The RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, beneficiary access to treatments, and identifying best practices for the care of those with rare diseases. It will also be tasked with helping coordinate state and federal activities regarding the research, diagnosis, and treatment of rare diseases, helping California better meet the needs of their constituents with often complex conditions. Since this council would include broad participation from the different health care sectors present in California including physicians, nurses, insurers, manufactures, and



researchers, it will also serve as an education resource to all stakeholders about the ways rare disease patients interact with our health care system.

In creating this council, California will be joining fourteen other states who have already enacted similar legislation in support of their rare disease community: Alabama, Connecticut, Illinois, Kentucky, Minnesota, Missouri, New Hampshire, New York, Nevada, North Carolina, and Pennsylvania, Tennessee, Utah, and West Virginia.

Once again, on behalf of the California rare disease community, we thank you for leading the effort to create a Rare Disease Advisory Council. NORD stands ready to help you secure the passage and swift implementation of this important legislation. For any questions, please feel free to contact NORD's Director of State Policy, Heidi Ross (hross@rarediseases.org). Thank you for your efforts!

Sincerely,

Heidi Ross
Director of State Policy

Earl Cole
Rare Action Network
California State Ambassador

Zhanzhi "Mike" Hu
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