NORD®
National Organization
for Rare Disorders

RARE CA

April 5, 2022

The Honorable Jim Wood
Chair
Assembly Committee on Health
State Capitol, Room 6005
Sacramento, CA 95814

RE: Support for Assembly Bill 1880

Dear Chair Wood and Members of the Assembly Committee on Health:

On behalf of the 1-in-10 Californians living with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for adding Assembly Bill 1880 (AB 1880) to the Assembly Committee on Health's meeting agenda. AB 1880 is common-sense legislation that would streamline and improve utilization management in California by requiring that a "clinical peer" of an ordering physician is making decisions regarding utilization management.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare 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. NORD believes strongly that all patients deserve the medical care that is best suited for their medical situation and will give them the best results.

AB 1880 builds upon patient protections previously enacted in California by ensuring that a clinical peer makes the decisions on utilization management protocols, such as step therapy and prior authorization, on behalf of health plans. Specifically, in order to review an appeal, a health care plan must designate a health care provider of the same or similar specialty as the health care provider who typically manages the medical condition or treatment under review. This is especially important in the rare disease context, as physicians engaged by health plans may lack the specialized experience and knowledge relevant to a rare disorder. This may lead to an extended appeals process or delayed access to effective treatment – resulting in medical setbacks, disease progression, loss of function, and even hospitalizations for the patient.

If enacted, AB 1880 will also require that data be compiled by health plans and health insurers around the use of utilization management protocols in case the Department of Managed Health Care and/ or the Department of Insurance requests the information. This data will improve overall transparency around the impact of utilization management protocols on patients in California and provide vital information to inform future policy making.

Once again, on behalf of the California rare disease community, we thank you for putting AB 1880 on the Assembly Committee on Health agenda and urge its swift passage. For any questions, please feel free to contact Ruby Dehkharghani at rdehkharghani@rarediseases.org.

Thank you for your consideration.

Sincerely,

Ruby Dehkharghani

Ruby Dehkharghani
Policy Analyst
National Organization for Rare Disorders