



April 28, 2017

Governor Terry Branstad
1007 Grand Ave.
Des Moines, Iowa 50319

Re: NORD Support Rare Disease Expert Provision in HF 653

Dear Governor Branstad:

On behalf of the 1-in-10 Iowans living with a rare disease, the National Organization for Rare Disorders (NORD) urges you to sign into law HF 653 with the rare disease “EXPERRT” provision wholly intact (Sec. 81 (d)).

NORD is the leading voice of the rare disease community dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Any disease affecting fewer than 200,000 Americans is considered rare. With nearly 7,000 rare diseases identified, and 30 million Americans affected, the population represented by NORD is extraordinarily diverse. Based on the reports we receive from member organizations, as well as individuals, it is increasingly difficult for health care policy makers to make decisions regarding rare patients without specific knowledge of rare diseases and their treatment.

Sec. 81 (d) of HF 653 will enact a vital new protection for these patients by ensuring that decisions regarding Medicaid beneficiary access to orphan medicines and biological products are made in consultation with outside rare disease experts. This proposed policy, known as Expertise in Review of Rare Treatments (EXPERRT), does not remove the state’s ability to implement appropriate utilization requirements, but rather ensures such policies are not haphazardly put in place without proper consultation.

Thank you for the opportunity to comment on this legislation. We look forward to seeing the “EXPERRT” provisions of HF 653 signed into law. If we can supply additional information, please do not hesitate to let us know. Sharon Ponce, NORD’s Iowa Volunteer State Ambassador, is available to assist as needed. Sharon can be reached via email at sharon.ponce@rareaction.org

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall".

Peter L. Saltonstall, CEO