



February 1, 2021

The Honorable Matt Williams  
Chair  
Banking, Commerce and Insurance Committee  
1445 K Street  
Lincoln, Nebraska 68508

RE: Support for LB 337

Dear Chair Williams:

Thank you for your service during these trying times. On behalf of the 1-in-10 individuals living in Nebraska with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for scheduling a hearing for Legislative Bill 337 (LB 337). LB 337 would provide a much-needed update to the state's step therapy law and NORD urges you to support this important legislation and swiftly move it out of your Committee.

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. 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. Based on the reports we receive from individuals affected by rare diseases, step therapy is increasingly being applied by health plans in Nebraska with little regard for a patient's treatment history and specific medical needs.

Step therapy, also known as "fail first," is an insurance company practice that requires patients to try and fail one or several medications chosen by their insurer before allowing them to take the medicine prescribed by their provider. Step therapy protocols vary widely among insurers. Navigating an appeal can be confusing and time consuming for patients and their health care providers, sometimes taking weeks or even months. This process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations.

We ask your support of LB 337 to allow patients better access to the appropriate treatments prescribed by their health care providers. This would be accomplished by:

- Ensuring step therapy protocols are based on widely-accepted medical and clinical guidelines;



- Creating a clear and expeditious appeals process – requiring a reply within 72 hours for an emergency or five calendar days for a non-emergency;
- Protecting patients who have already tried and failed a drug or for whom a drug is expected to be ineffective;
- Protecting patients whose conditions are well-controlled on a prescription from being required to try a new medication against their provider’s recommendation or for whom the medication is contraindicated or likely to cause harm; and
- Protecting patients when their provider recommends a specific medication due to medical necessity.

It is important to note that LB 337 does not ban the use of step therapy. However, in order to guarantee patient safety, Nebraska needs to ensure that step therapy policies do not interfere with appropriate care for rare disease patients and families. By voting in support of LB 337, you will be protecting patients, while still enabling health plans to achieve the cost saving benefits of step therapy when appropriate. Given the additional challenges of the COVID-19 pandemic, now is a logical time to pass step therapy protections into law to avoid some of the unnecessary burdens on patients, providers and the health care system that could be prevented with appropriate and timely care.

Once again, on behalf of the Nebraska rare disease community, we thank you for putting LB 337 on the Banking, Commerce and Insurance Committee’s agenda and urge its swift passage. For any questions, please feel free to contact Alyss Patel at [APatel@rarediseases.org](mailto:APatel@rarediseases.org). Thank you for your consideration.

Sincerely,

Alyss Patel  
State Policy Manager, Western Region  
National Organization for Rare Disorders

CC: Members of the Banking, Commerce and Insurance Committee