April 15, 2021

The Honorable Nellie Pou
Chair
Senate Commerce Committee
100 Hamilton Plaza
Suite 1405
Paterson, NJ 07505

Re: Support for Senate Bill 3051

Dear Chairwoman Pou and Members of the Senate Commerce Committee:

On behalf of the 1-in-10 individuals living in New Jersey with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your service during these trying times. We encourage you to support Senate Bill 3051 (S3051) by adding it to the Senate Commerce Committee’s next meeting agenda. S3051 would ensure that when step therapy is used in New Jersey, it is safe for patients, clinically grounded, and transparent to patients and health care providers.

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.

Step therapy policies, also known as fail first, are used in an attempt to control costs by forcing patients to try and “fail first” on an alternative medication before approving access to the medication that was originally prescribed to them by their health care provider. 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, which may ultimately lead to increases in health care costs.

S3051 would reform step therapy processes and enable better patient access to the appropriate treatments prescribed by their health care providers. This would be accomplished by:

- Ensuring that step therapy protocols are based on widely accepted medical and clinical practice guidelines;
• Creating a clear and expeditious process to request a medical exception and requiring a response by the patient’s health plan within 72 hours for non-emergency situations and 24 hours for emergency situations; and

• Providing certain circumstances for a patient to override the step therapy protocol when the drug required under the step therapy protocol is contraindicated or will likely cause an adverse reaction of physical or mental harm.

It is important to note that S3051 does not ban the use of step therapy. However, to guarantee patient safety, New Jersey needs to ensure that step therapy policies do not interfere with appropriate care for rare disease patients and families. S3051 would protect 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 reform the state’s step therapy practices 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 New Jersey rare disease community, we thank you for reviewing S3051 and urge its swift addition to the Senate Commerce Committee’s next meeting agenda. For any questions, please contact Annissa Reed at AReed@rarediseases.org. Thank you for your consideration.

Sincerely,

Heidi Ross
Director of Policy
National Organization for Rare Disorders

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the Senate Commerce Committee