May 23, 2018

Governor Sununu
Office of the Governor
State House
107 North Main Street
Concord, NH 03301

Re: Support for House Bill 1791

Dear Governor Sununu:

On behalf of the 1-in-10 people in New Hampshire living with a rare disease, the National Organization for Rare Disorders (NORD) respectfully requests you to sign House Bill 1791, an act regarding the substitution of interchangeable biologic products (biosimilars) approved by the Food and Drug Administration (FDA), into law. The bill has the potential to benefit many of our organization’s members, and it will protect patients by including language calling for prescriber communication. By signing this piece of legislation into law, you will be benefiting numerous patients suffering from rare disorders in New Hampshire.

According to the legislation, pharmacists will be required to communicate to patients and their prescribing physician any and all dispensations of a substitute biological product for another biologic drug. NORD applauds the development of these innovative and valuable therapeutic treatments and supports the increased access that biological products will offer rare disease patients. Yet, due to the distinctions between biologics, any substitution of a biological product must include communication between the prescriber and pharmacist to keep patient safety a top priority.

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 heterogeneous. We believe strongly that every patient deserves the medical care that is best suited for their medical situation and that is most likely to give them the best results. Based on the reports we receive from member organizations as well as individuals, it is increasingly difficult for rare disease patients to receive optimum care if any degree of customization is required.

In light of this challenge, prescriber communication between the pharmacist and prescriber about which biological product is dispensed can help ensure all rare patients receive optimum care.
Biological products differ from generics in that they are not identical to their biologic counterpart. Due to the sensitive manufacturing process of biological products, even the slightest change can have a significant negative impact on a patient’s therapeutic regimen. This is a serious issue for a large segment of the rare disease community because not all drugs work the same for every patient, especially when dealing with unpredictable disease progression.

In order to guarantee patient safety, health care providers need to know which medicine was dispensed to the patient, whether a substitution was made, and, if so, to what alternative product. These factors are critical and need to be taken into consideration when supplying a patient with medication.

NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Patients in the rare disease community experience many unforeseeable variables and outcomes. By securing effective biological product substitution laws, New Hampshire can ensure prudence in prescriber communication that has the potential to dramatically alter a course of treatment.

Once again, on behalf of NORD and the millions of Americans who face the struggles of a rare disease, we appreciate the opportunity to comment on this legislation. We strongly urge you to sign into law HB 1791, which includes prescriber communication and will ensure that increased access to this new age of medicines is done in a safe, reliable, and consistent way for patients and physicians.

If we can supply additional information, please do not hesitate to let us know. I can be reached at (202) 545-3830 or via email at boyd@rarediseases.org.

Sincerely,

Tim Boyd, MPH
Director of State Policy

Cc: Kim Pang, NORD Volunteer State Ambassador for New Hampshire