



September 20, 2019

Senator James Welch
Chairman
Joint Committee on Financial Services
24 Beacon Street
Room 413-B
Boston, MA 02133

Representative James Murphy
Chairman
Joint Committee on Financial Services
24 Beacon Street
Room 254
Boston, MA 02133

Re: Support for H.898 and H.926

Dear Chairman Welch and Chairman Murphy:

On behalf of the 1-in-10 individuals in Massachusetts with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support two bills moving through the House of Representatives in the Commonwealth of Massachusetts H.898 and H.926.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

A rare disease is defined as any disorder that affects 200,000 or fewer people in the United States. There are over 7,000 such disorders that have been identified, and over 90 percent of them do not have a treatment approved by the Food and Drug Administration.¹ Even when a treatment exists, however, access is not assured. Due to the innovative nature of many of the treatments for rare diseases and the small populations they are intended to treat, these therapies can be expensive. Thankfully, both charitable and manufacturer-based programs exist to help rare disease patients defray the cost.

As you know, H.898 and H.926 affirm that cost-sharing amounts paid by either the insured or on behalf of the insured by another person for prescription drugs count towards a patient’s insurance policy. Cost-sharing includes the coverage limit, copayment, coinsurance, deductible or out of pocket expense requirements associated with an individual’s health plan.

NORD recognizes that the high cost of drugs has a direct impact on patient access. Addressing this and other barriers to care is a priority for NORD. However, failing to support patients today, who are in need

¹ Orphan Drugs in the United States; Exclusivity, Pricing and Treated Populations. Report. IQVIA Institute for Human Data Science. 2018. Accessed February 6, 2019. <https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/orphan-drugs-in-the-united-states-exclusivity-pricing-and-treated-populations.pdf>.



of immediate assistance to pay for their prescribed treatment, will have a devastating impact on their health.

Cost is a primary reason why patients decline to fill their prescriptions.² Further, non-adherence to prescribed medication is responsible for an estimated 125,000 deaths, ten percent of hospitalizations, and hundreds of billions of dollars in costs to the healthcare system per year.³

With this in mind, it is critical that payments made by patients, or on behalf of patients, apply toward their deductible and yearly maximum out-of-pocket costs. Without applying payments in this manner, patients will be less likely to meet their deductible and, thus, may quickly exhaust any charitable or manufacturer-based assistance they may have by repeatedly paying for the full cost of the drug. If that happens, patients will be left having to pay the bulk of their deductible as well as the entirety of their copay or coinsurance, despite having already spent enough to meet their deductible, and could be forced to decide between forgoing their critical therapy or facing medical bankruptcy.

H.898 and H.926 would greatly help rare patients and families in Massachusetts avoid that tough choice between critical therapy or medical bankruptcy. In addition, this legislation will ensure that they have access to their needed prescribed therapies without any interruption due to medical non-adherence or bankruptcy.

Thank you for the opportunity to comment on this legislation. We look forward to continuing to work with you on H.898 and H.926, to ensure that rare disease patients in Massachusetts are supported in their daily struggle to afford their medications. If you have any questions, do not hesitate to contact me at rsher@rarediseases.org, or 202-545-3970. Thank you again for your consideration.

Sincerely,

Rachel Sher
Vice President of Policy and Regulatory Affairs

CC:

Joint Committee on Financial Services Members

² Health Poll: Prescription Drugs. Report. NPR, Truven Health Analytics. 2017. Accessed February 6, 2019. http://truvenhealth.com/Portals/0/Assets/TRU_18156_0617_NPR_Poll_Prescription_Drugs_FINAL.pdf

³ Viswanathan M, Golin CE, Jones CD, Ashok M, Blalock SJ, Wines RC, et al. Interventions to Improve Adherence to Selfadministered Medications for Chronic Diseases in the United States: A Systematic Review. *Ann Intern Med.* ;157:785–795. doi: 10.7326/0003-4819-157-11-201212040-00538; Brody, Jane E. "The Cost of Not Taking Your Medicine." *The New York Times*, April 17, 2017. Accessed February 6, 2019. <https://www.nytimes.com/2017/04/17/well/the-cost-of-not-taking-your-medicine.html?login=email&auth=login-email>.