October 6, 2020

Representative Brandt Iden
Chair
House Ways and Means Committee
Anderson House Office Building
124 North Capitol Avenue
Lansing, MI 48933

Re: Support for House Bill 5944 – a bill related to prescription drug copay assistance

Dear Chairman Iden,

On behalf of the 1-in-10 individuals in Michigan with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support House Bill 5944 (HB 5944), a bill related to prescription drug copay assistance, without tie-barring it to any other piece of pending legislation. HB 5944 is important to the rare disease community, and we appreciate your efforts to swiftly move this bill forward when your committee considers it.

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. However, even when a treatment exists, access is not guaranteed. 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 and often do not have a generic equivalent available. Thankfully, both charitable and manufacturer-based programs exist to help rare disease patients defray the cost.

As you know, under HB 5944, all payments made by or on behalf of the insured must apply towards a patients’ cost-sharing requirements. Cost-sharing is defined under the bill as any copayment, coinsurance, deductible, or annual limitation on cost sharing 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. Cost is a primary reason why patients avoid filling their


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prescriptions. 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.\textsuperscript{3,4}

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 be able to meet their deductible and, thus, may quickly exhaust any charitable or manufacturer-based assistance they may have and still be responsible for high copays or coinsurance. 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. Patients could be forced to decide between forgoing their critical treatment or facing medical bankruptcy. HB 5944 would greatly help rare disease patients and families in Michigan avoid that tough choice.

Thank you for the opportunity to comment on this legislation. We look forward to working with you on HB 5944, to ensure that it passes without tie-barring it to other legislation, as rare disease patients in Michigan need this support in their daily struggle to afford their medications. If you have any questions, please do not hesitate to contact me at hross@rarediseases.org. Thank you again for your consideration.

Sincerely,

Heidi Ross
Director of Policy

CC: House Ways and Means Committee Members

