



May 16, 2018

Senate Health and Human Services Committee  
State House  
Providence, RI 02903

*Transmitted via email to [Slegislation@rilegislature.gov](mailto:Slegislation@rilegislature.gov)*

Dear Chairman Miller and Members of the Committee:

On behalf of the 1-in-10 Rhode Island residents with one of the 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to express concern with S 2532, an act pertaining to prescription drug benefits and prescription drug marketing.

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 assistance services.

After reviewing S 2532 and consulting with our member organizations, we have concerns regarding a provision in the legislation that allows insurers to “[a]dopt a method to calculate the out-of-pocket maximum that only accumulates toward the maximum those payments made by the insured.”<sup>1</sup> If enacted, this policy, also known as “copay accumulators,” will severely and suddenly increase out-of-pocket costs for many rare disease patients.

Patients are harmed under copay accumulator programs because costs that were previously borne by insurers are shifted onto patients in the middle of their plan year. It is well established that substantial cost increases of this type lead to patients abandoning treatment and suffering worse health outcomes because they can no longer afford their medicine. Rare disease therapies tend to cost more than other classes of drugs because of their smaller patient populations. Therefore, the harmful effects of copay accumulator programs will disproportionately impact rare disease patients and their families.

NORD recognizes that the intent of the committee is not to harm patients but, rather, to prevent copay assistance from artificially increasing demand for more expensive forms of treatment and, thus, increasing health care costs overall. While there are certainly instances in which this type of reform should be examined (such as when multiple generic options are available for a given treatment), copay accumulator programs will be applied to all forms of treatment, even if there are no cheaper therapeutically equivalent medicines available for patients to take. In these

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<sup>1</sup> 2018 S 2532 Sec. 1(d)(2)



instances, copay accumulator programs make it much harder for patients to secure the only medicine approved by the Food and Drug Administration (FDA) available to treat their condition.

What is more, NORD is troubled by the fact that, if this legislation is enacted, many in our community could be faced with an entirely unexpected and expensive, possibly even prohibitively expensive, bill for their medication due to a lack of awareness of these programs and what they do. The complete effect of this policy change will be to not only raise costs for patients but to do so in a way that leaves many completely unprepared and uninformed as to what has happened.

In order to address this issue, we encourage the committee to re-examine and remove provisions in this legislation that will proliferate the use of copay accumulator programs in Rhode Island. Thank you for the opportunity to comment on this legislation and please reach out to NORD if you have further questions.

Sincerely,

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