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May 31st, 2024

The Honorable Liz Krueger, Chairwoman Senate Finance Committee 172 State Street, Capitol Building Room 416 Albany, NY 12247

RE: S.2393A – Share the Savings - Support

Dear Chairwoman Krueger,

The Global Healthy Living Foundation (GHLF) supports Senate Bill 2393A and hopes that the committee will vote on it favorably. This legislation would ensure that patients can realize the full benefit of the deals and rebates that insurers and pharmacy benefit managers (PBMs) negotiate with drug manufacturers.

By way of background, GHLF is a New York-based 25-year-old 501(c)(3) patient organization reaching millions of chronically ill patients and their caregivers across the country through social media, community events and our online support and education. GHLF works to improve the quality of life for patients living with chronic disease by making sure their voices are heard and advocating for improved access to care at the local level. Our patients have chronic conditions including arthritis, psoriasis, gastrointestinal disease, cardiovascular disease and migraine. As a result, these patients incur significant financial burden due to the high cost of the treatments that are necessary to manage their life-long disease. And, it is on behalf of the patients we represent that we write to express our support for S.2393A.

Through often proprietary and non-disclosed arrangements, PBMs offset their acquisition costs for drugs which have high list prices via rebates provided by the manufacturer – effectively lowering the net cost of the drug. However, this rebate is not used to offset beneficiary costs, and, in addition, patients are often directed to high list-priced drugs due to the design of the formulary. In fact, the patient's coinsurance isn't a percentage of the net price paid by the PBM, but rather a percentage of the list price. Often, patients are paying more out-of- pocket for the prescription than their insurance plans, which will only continue to increase as manufacturers inflate list prices to recoup losses from the rebates and other discounts.

GHLF firmly believes that the success of any efforts to reduce drug prices should be measured by the reduction of financial burden on patients and the ability of patients to access the treatment deemed best for them in consultation with their health provider. For that reason, we support this effort to ensure that at least 75 percent of the rebates and fees negotiated by insurers and PBMs are passed on the patients.

The opaque negotiations and arrangements between PBMs and manufacturers create perverse incentives to keep list prices high. As a result, both the pharmaceutical and insurance industries financially benefit while patients encounter coinsurance and other out-of-pocket expenses often making therapies inaccessible to them. We often hear stories from our patients about walking away from the prescription counter unable to pay for their medications, rationing or skipping doses to make one prescription last longer. For a patient with a chronic disease like arthritis or Crohn's disease, consistent adherence to treatment is necessary to keep their symptoms under control and prevent flare-ups that not only lead to their disability and reduced quality of life, but have the potential to unnecessarily burden the healthcare system overall leading to greater expenditures.

In the past, GHLF has submitted comments to the United States Department of Health and Human Services in which we expressed support for a 100 percent mandatory rebate pass-through policy to patients up to the amount of their total out-of-pocket costs each year. It is not fair for a person with a chronic disease to bear the burden of high costs, effectively reducing costs for healthy people. To guarantee the effectiveness of this proposed legislation, there should be a requirement for a definitional agreement for certain terms that are frequently used by PBMs. We believe strict definitions and mandatory transparency requirements are needed to stop entities from gaming the system by reclassifying money and avoiding pass-through obligations.

In the end, our goal is for beneficiaries to experience reduced healthcare costs and we believe that, while this bill does not achieve the 100 percent mandatory pass-through, it goes far enough to ensure that patients will benefit from negotiated rebates. We understand that forcing insurers and PBMs to pass savings through to patients may result in high premiums and while higher premiums are undesirable, in the end, the actual savings chronically ill patients would see from the reduction in out-of-pocket costs for their prescriptions would result in overall lower, more transparent costs for them. For this reason, we offer our support for S.2393A.

Time is of the essence for those residents living with a chronic illness and paying exorbitant medical costs. For the reasons listed above, we respectfully ask that you support Senate Bill 2393A. We appreciate your thoughtful consideration of this legislation and would be pleased to provide any further information that you may require.

Respectfully submitted,

Corey Greenblatt

Associate Director, Policy and Advocacy Global Healthy Living Foundation

CC: Senate Health and Human Services Committee



