June 6, 2019

The Honorable Mitt Romney  
124 Russell Senate Office Building  
Washington, D.C. 20510

The Honorable Mike Braun  
374 Russell Senate Office Building  
Washington, D.C. 20510

Dear Senator Romney and Senator Braun,

On behalf of the more than eight million Americans living with psoriasis and psoriatic arthritis, the National Psoriasis Foundation (NPF) write today in strong support of S. 1384, the Prescription Drug Rebate Reform Act of 2019. NPF strongly supports this legislation and we appreciate your commitment to increasing drug pricing transparency and reducing out-of-pocket costs for patients.

As you know, the current framework of the drug rebate system is not managed in a way that is beneficial to patients, particularly those with chronic illnesses like psoriasis and psoriatic arthritis who often have high out-of-pocket costs to manage their disease. As currently constructed, the rebate system drives our patients’ treatment costs higher and higher annually and ultimately limits psoriatic patients from access to costly life-changing drugs. Earlier this year, the Department of Health and Human Services (HHS) Secretary Azar highlighted a story about a patient with a chronic disease whose experience sounded much like those of our community.

The woman was facing financial struggles to secure the treatments needed to manage her chronic disease stating:

“The sticker price for a year’s treatment on this drug runs into the tens of thousands of dollars. Sue was told that her out-of-pocket costs for the drug would be $7,200 a year on her Medicare part D plan. When she heard that price, she said she just broke down and cried. She simply couldn’t afford it.”1

Unfortunately, this is not an isolated incident for patients with psoriatic disease. On a daily-basis, too many patients are attempting to manage their condition by navigating rising drug prices and out-of-pocket costs. According to a recent study, the annual treatment costs for tumor necrosis factor [TNF] inhibitor drugs, one of the leading types of treatments for those with psoriatic disease, increased by 144% from $15,809 per year in 2009 to more than $38,000 in 2016.2 Bearing in mind the connection between drug prices and out of pocket costs, it is easy to understand how individuals with chronic

1 https://bipartisanpolicy.org/events/a-keynote-address-from-hhs-secretary-alex-m-azar-ii/
Diseases are challenged in managing their disease. Drug manufacturers often blame the current rebate system for driving increases in list price. As one pharmaceutical executive outlined, “[we retain about 50% of the list price] the rest goes to subsidize profitability of pharmacy benefit managers (PBMs), insurance companies and frankly premiums of those that are healthy.”

While we do not agree entirely that rebates are to blame for the difference between list price and net price, we acknowledge the complexities of the problem and we believe your proposal will make it more difficult for manufacturers to defend increases in list prices and potentially result in lower list prices.

We were pleased to see that you emphasized the inverse relationship between the high cost of treatment and patient adherence to medication by stating, “…[the current rebate system] puts consumers’[patients] health at risk—as many struggle to adhere to their medication routine as a result of high list prices.” Unfortunately, patients with psoriatic disease are all too familiar with the burden that comes with the high cost of treatment, which can result in reduced access, outcomes and overall well-being. A 2018 NPF Advocacy survey of NPF members found that nearly 50 percent of psoriasis and psoriatic arthritis patients, many of whom live on a fixed income, experienced financial strain due to the cost of their treatment. Equally alarming, almost one in four patients with psoriatic disease spend more than $150 per month in out-of-pocket costs to access treatment needed to manage their chronic condition. We recognize and studies show that patient adherence decreases as out-of-pocket costs rise. In fact, just a $10 increase in expected out-of-pocket costs results in a nearly 5 percent drop in patient adherence.

Additionally, we applaud your approach and focus on net price instead of list price when determining what should count towards a patient’s coinsurance obligations. We believe that this could result in lower out-of-pocket costs and ultimately, greater patient adherence to treatments. In fact, the Institute for Clinical and Economic Review (ICER) issued the Targeted Immunomodulators for the Treatment of Moderate-to-Severe Plaque Psoriasis: Effectiveness and Value Draft Evidence Report echoed this recommendation, “[ICER’s recommendations included encouraging payers to….base co-payment and/or co-insurance for therapies [treatments] on prices of net of discounts and rebates instead of list price.”

We are also concerned about the ability of patients with chronic illnesses like psoriasis and psoriatic disease to access treatment options, which are further complicated by the different formulary designs and utilization management policies across PBMs and third-party payers. Unfortunately, these formulary and utilization management policies, like prior authorization and step therapy, are often based on rebates and manufacturer concessions rather than on clinical practice standards or care guidelines. This means patients with psoriatic disease and their physicians often have their choice in drugs dictated by out-of-pocket and other cost burdens rather than the efficacy of the drug. This is

3 https://www.wsj.com/articles/flip-the-script-drugmakers-blame-middlemen-for-price-hikes-11549364401
5 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278192/
6 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278192/
particularly alarming for patients with psoriasis and psoriatic arthritis who are frequently at risk of developing additional chronic conditions as a result of their psoriatic disease diagnosis. As guidelines published in 2019 by the National Psoriasis Foundation (NPF) and the American Academy of Dermatology (AAD) indicate, individuals with psoriatic disease are at a heightened risk of developing a number of comorbid conditions including cardiovascular disease and stroke, diabetes and hypertension, as well as depression and anxiety.¹

On behalf of the millions of Americans who live with psoriatic disease, we appreciate your attention to this critically important issue and welcome the opportunity to work together to increase transparency in treatment pricing, reduce out-of-pocket costs for patients, and remove barriers for patients to access the treatment options necessary to manage their conditions. Should you wish to reach us to discuss any of our suggestions please contact Matthew Moran, Federal Government Relations & Health Policy Manager at mmoran@psoriasis.org.

Sincerely,

Patrick Stone
Vice President, Government Relations & Advocacy

¹ https://www.jaad.org/article/S0190-9622(18)33002-0/fulltext