July 26, 2023

Ron Wyden
Chair, Committee on Finance
U.S. Senate
Washington, DC 20510

Mike Crapo
Ranking Member, Committee on Finance
U.S. Senate
Washington, DC 20510

Dear Chair Wyden and Ranking Member Crapo:

On behalf of the nearly 60 million American adults and 300,000 children living with arthritis, the Arthritis Foundation would like to provide the patient perspective on prescription drug affordability and accessibility as the Committee considers legislation around Pharmacy Benefit Manager (PBM) reform. Many people living with arthritis rely on high-cost specialty medications to manage their disease and are deeply impacted by PBM policies. We appreciate the attention the Committee is paying to health costs and policies that hinder access to care for patients, including measures that focus on specialty pharmacy requirements, address spread pricing, and require more transparency about out-of-pocket costs and formulary design.

Last year we surveyed our patient population in response to the Federal Trade Commission (FTC) request for information on patient impact of PBMs. We received 834 responses to our survey, and the findings from the survey have shaped our policy positions for the 118th Congress. Overall, the survey showed that PBMs hold enormous influence over patients' ability to access and adhere to their medications and that patient experiences are highly sensitive to shifts and changes within PBM coverage policies. Access impacts result from a range of policies from medication substitutions (experienced by 39% of respondents); steering towards specific pharmacies (experienced by 75% of respondents with 57% experiencing difficulties); requirement to use mail-order pharmacy (experienced by 69% of respondents with 60% experiencing negative consequences); in addition to the many difficulties presented by inappropriate utilization of protocols like step therapy and prior authorization.

The Arthritis Foundation has long advocated for "system-wide transparency" and the need to look at the drug supply chain holistically. It is too interconnected to single out one industry, and while we recognize legislative hearings and mark-ups may focus on specific sectors, we urge the Committee to consider whole-sale reform to address the root of the problems around prescription drug costs, especially through the lens of chronic disease patients who may rely on lifetime access to care and treatment to manage their disease.

We would like to offer the following comments on the provisions under consideration for the mark-up:

We are generally supportive of efforts to require more transparency about PBM practices. In particular we want to acknowledge the proposed requirement for PBMs to disclose when a

biosimilar product has higher cost-sharing than the reference product or is subject to utilization management for which the reference product is not subject. When the first adalimumab biosimilar for Humira came to market earlier this year, at least one major PBM required patients to fail on the reference product before gaining access to the biosimilar, effectively shutting the biosimilar out of the market. Without the ability to gain market share, biosimilar medications cannot reach patients and achieve the promise of lower costs for patients. Further, these types of utilization management protocols are not aligned with clinical guidelines and add administrative burdens to both providers and patients. Coupled with requirements to report cost-sharing for a 30-day supply of the reference product and a 30-day supply of the biosimilar had it been available on formulary, these types of data points will help health care stakeholders advocate for better access to lower-cost medications. Arthritis Foundation data demonstrates that inappropriate utilization of step therapy practices can lead to delays in care, resulting in negative financial, emotional, and physical consequences, and patients living with arthritis are particularly susceptible to these kinds of insurance practices.

We support the Committee's focus on PBM-owned specialty pharmacies and the impact requirements to utilize those pharmacies have on patients. As indicated above, 75% of respondents in our 2022 survey indicated they were required to use a specialty pharmacy, with 57% reporting associated challenges. Commonly cited challenges included: long phone wait times; delays and lag times in receiving medications that would not otherwise have happened with a local pharmacy; onerous requirements; and lack of personal medication management assistance.

We welcome the opportunity to bring the patient perspective to the work of the Finance Committee as you continue working towards PBM reform. Should you have any questions or if we can be of assistance, please contact Alisa Vidulich Casavant, Policy Director, at avcasavant@arthritis.org or 202-235-2037 or Anna Hyde, VP of Advocacy and Access, at ahyde@arthritis.org or 202-843-0105.

Sincerely,

Anna Hyde

Anna Hyde
Vice President of Advocacy and Access
Arthritis Foundation