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Colorado Drug Pricing Review Board September 24, 2024

**Subject: Patient Commentary on Proposed Rule Changes** 

Hello,

My name is Corey Greenblatt, and I am commenting on behalf of the more than one million chronically ill patients living in Colorado and the thousands of patients who rely on the medications under review to live their daily lives, whom GHLF represents. Thank you for allowing me to comment today regarding the proposed draft changes to the PDAB policies and rules. While the effort to reduce drug prices is one of the most pressing concerns in our current healthcare system and we support the board's goal to do so, we are concerned with some of the proposed changes and how they may impact patient participation at these meetings moving forward.

By background, GHLF is a non-profit patient group that works to improve the quality of life for people with chronic disease, often focusing on those least able to advocate for themselves. Through our websites, social media channels, and conventional media, GHLF reaches more than 10 million chronically ill people monthly in the United States – in English and Spanish. Our patient community is often forced to try multiple medications before finding the one that works best for them. Once they find something that works, regardless of what it is, they hesitate to give it up and try something new. However, in our patient community it is very common for medications to lose their effectiveness and force patients to switch to new options. Just because a patient is not currently taking a medication does not mean it will not be an option for them in the future.

GHLF is appreciative of the Board for taking the time to listen to various stakeholders and for slowing down the process in order to implement changes to their policies. This is to make sure that mistakes are not made in the pursuit of speed. However, we are concerned about one of the proposed changes being considered by the Board, which could restrict the participation of certain types of patients and caregivers in stakeholder meetings.

In the field of patient advocacy, we often rely on patients who can represent others like themselves, even if they have not personally experienced the specific policy under discussion. For example, a patient doesn't need to have experienced Step Therapy or other access issues firsthand to speak about the fear of going through it, or the potential outcomes if access to their medication was at risk due to those policies. Similarly, patients who have not been prescribed a medication currently under review can still speak about the fear they would face if their medication access was impacted by the decisions made by the Board, and can be representative members of their community who were unable to participate.

Furthermore, the proposed changes do not address whether a patient who previously used a medication but currently does not is able to participate in these meetings, despite having firsthand

experience with the medication. Or whether patient and caregiver advocacy groups that speak on behalf of patients who are unwilling or unable to speak for themselves are able to continue to do so. All of this underlines the point that we should be doing everything we can to increase patient participation in these meetings by casting a wider net, rather than further trying to limit it by seeking the "perfect patient."

We appreciate the Board's openness to listening to stakeholders and considering input from a wide range of parties. However, we urge the final proposed rules and policies to eliminate any language that restricts patient participation.

Sincerely,
Corey Greenblatt
Director, State Policy and Advocacy

