



October 16, 2024

Colorado Prescription Drug Affordability Board
Colorado Division of Insurance
1560 Broadway, Suite 850
Denver, CO 80202

Re: Draft Prescription Drug Affordability Board Policy and Procedures

Dear Members of the Colorado Prescription Drug Affordability Board:

Aimed Alliance is a non-profit health policy organization that seeks to protect and enhance the rights of health care consumers and providers. We appreciate the opportunity to provide feedback on the recent updates to the Board's policy and procedures. While we acknowledge the Board's efforts to improve engagement with consumers, we are writing to express our concerns about the amendments to the orphan drug designation and patient and caregiver input processes.

I. Consideration of Consumer Cost Savings

In the United States, setting the price for a prescription drug is an incredibly complex process, with pharmacies, drug manufacturers, health plans, and pharmacy benefit managers all playing a role. As costs shift between different members of the chain, cost savings are often not passed down to consumers. Therefore, we commend the Board for recognizing that during an affordability review, the Board should consider how drug prices impact consumers' cost-sharing and premiums, and whether negotiated savings from rebates are passed down to consumers. We urge the Board to ensure that these considerations are genuinely considered in determining whether a prescription drug is affordable, and how a potential UPL could impact patient access.

In addition, we applaud the Board's decision to extend the submission deadline from 60 to 90 days. These modifications represent a positive development towards better integrating patient perspectives and understanding how patients may be affected by the Board's decisions.

II. Rare Disease and Orphan Drugs

Aimed Alliance supports the Board's decision to modify its policy to consider orphan drug status and consult with the Colorado Rare Disease Advisory Council (RDAC), as RDACs have important knowledge and experience with the unique access and affordability challenges facing patients with rare diseases.

Considering the unique needs of these patients is critical because many of these patients do not have alternative treatments to manage or treat their conditions. Moreover, many individuals may wait years or decades for an effective treatment and can share insights on how consumers with rare diseases find value in their treatments. Lastly, given the smaller population size of rare disease communities, the research and investment infrastructure surrounding these treatments is different than other conditions. As such, the Board should consider how a UPL may impact the incentives to invest in, research, and develop treatments for rare disorders. Therefore, given the



complexity of rare diseases, Aimerd Alliance urges the Board to exclude orphan drugs from the PDABs consideration.

III. Patient Engagement and Input

Lastly, we are concerned that the updates to the policy to limit patient and caregiver engagement solely to individuals who have been prescribed the drug under review will limit the Board's understanding of the value of a treatment and its affordability. Specifically, we are concerned that under the amended policy, patient and caregiver advocacy organizations would be unable to provide feedback to the Board on how a particular drug is used by their disease community.

The perspectives of patient and caregiver advocacy organizations are important, as they provide a broader perspective on the access and affordability issues experienced by patients and caregiver communities. Moreover, certain chronic conditions, such as HIV/AIDS, face stigmatization, causing patients and caregivers to feel uncomfortable publicly identifying as someone who uses a medication to treat a stigmatized condition. As such, advocacy organizations provide the opportunity to anonymize individual stories while nonetheless ensuring the Board receives the information and data it needs to make an appropriate affordability decision.

Advocacy organizations also play an important role in amplifying the voices of patients and caregivers who may not be able to participate in a Board meeting due to time, work, or other constraints. Thus, allowing broader input from patient and caregiver advocacy groups would help ensure the Board's affordability review is inclusive of these perspectives and has comprehensive understanding on the access and affordability challenges related to a selected prescription drug.

In conclusion, we strongly urge the Board to remove this limitation to ensure the Board can hear diverse perspectives on the affordability for selected prescription drugs. Thank you for your time and consideration.

Sincerely,

Olivia Backhaus
Staff Attorney
Aimerd Alliance