



ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

December 4, 2024

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

RE: Comments on PDAB Policy and Procedures: Policy No. 4 and Rule 3 CCR 702-9:
Part 1 - General Provisions and Part 3 - Affordability Reviews of Prescription Drugs

Dear Chair Mizner and Members of the Colorado Prescription Drug Affordability Board (PDAB):

The Ensuring Access through Collaborative Health (EACH) Coalition is a network of national and state patient organizations and allied groups that advocate for treatment affordability policies that consider patient needs first.

We appreciate the opportunity to provide input on PDAB Policy and Procedures: Policy No. 4 (Policy) and Rule 3 CCR 702-9: Part 1 - General Provisions and Part 3 - Affordability Reviews of Prescription Drugs (Rule). On behalf of the undersigned organizations and the patients they represent, we urge the board to consider the enclosed recommendations to allow for robust input from patients and their representatives throughout the affordability review process.

Utilize Patient Organizations for Insight Into Patient Needs and Perspectives

We commend the board for including in both the Policy and Rule opportunities for patients and caregivers to provide direct input to the board throughout the drug review process. As patient advocates, we encourage policymakers to gather patient perspectives to improve policy decisions and ensure laws and regulations serve patient needs.

However, for reasons ranging from privacy to time constraints, patients and caregivers without prior advocacy experience can be unable or unwilling to participate. Patient organizations understand the life cycle of disease from the lens of prevention, diagnosis, and disease management and can also offer critical input and perspectives on patient needs. Therefore, it is especially important that organizations that represent the population of patients who rely on the medication under review can provide specific insights to the board throughout the process.

Therefore, we strongly urge that the board ensure all stakeholders, including patient organizations, are afforded the same opportunities to provide input to the board on all topics. Due to ambiguities in language throughout the Rule and Policy, we believe the input of patient organizations will be limited or overlooked.

We urge you to add patient organizations as a vital stakeholder group throughout both documents, providing fair and equal participation for everyone. **Specifically, patient organizations should be included among the stakeholders who will be allowed and encouraged to provide input on drugs under review in the AR Rule, Section E: Conducting an Affordability Review, Item 2.h, "Input from Specified Stakeholders".**

Additionally, we recommend that patient organizations be added as a stakeholder group from which input will be considered in the AR Policy, Section B: Compiling Evidence and Information for Required Factors, Item 8 "Input from Specified Stakeholders". As currently

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written, patient organizations are limited to offering input on best practices on how to gather information from patients. Failing to allow patient organizations to also provide input on the drugs under review would unnecessarily limit a vital source of information on patient experiences and needs.

Utilize Patient Organizations as Data Collection Partners

There are many proven methods patient organizations have used to collect meaningful, unaltered data from patients (including discussion sessions, surveys, etc.) that we could facilitate, acting as a bridge between the board and patients, enabling more voices to be heard. This data can be shared and outreach can be conducted in a manner that ensures transparency and protects raw patient data, thus increasing board access to real-world patient data without any perceived bias. Given past challenges for the Board to collect patient data, in addition to staff time and budget limitations, we feel our participation can fill these gaps.

As we have outlined during multiple meetings and comments, the patient survey utilized by the board for the first round of affordability reviews demonstrated fundamental issues in both question design and analysis. As a result, patients were unable to provide key context into “why” a drug was considered affordable or unaffordable.

As requested, we are submitting to the board, as an attachment to this letter, an alternative survey design created by patient research partners and patient organization leaders in our Patient Inclusion Council, which was also reviewed by research professionals for accuracy. We urge the board to consider this survey and design, which aims to accurately capture patient perspectives and determine the root cause of affordability challenges for patients. We also encourage the board to consider collaborating with EACH/PIC and patient research partners to work with your data scientist in the next rendition of data collection, ensuring question design is clear and contextual factors are identified.

We invite all opportunities to speak directly with any board member who would be interested in more detailed perspectives from our national network of patient organizations and allied groups.

Sincerely,

Ensuring Access through Collaborative Health (EACH) Coalition
Advocates for Compassionate Therapy Now
AiArthritis
Aimed Alliance
Alliance for Aging Research
Arthritis Foundation
Autoimmune Association
Biomarker Collaborative
Caring Ambassadors Program
CF United
Chronic Care Collaborative
Chronic Care Policy Alliance
Chronic Disease Coalition
Coalition of State Rheumatology Organizations
Color of Gastrointestinal Illnesses
Community Liver Alliance
Crohn's & Colitis Foundation



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Exon 20 Group
Global Healthy Living Foundation
HIV + Hepatitis Policy Institute
ICAN, International Cancer Advocacy Network
Immune Deficiency Foundation
Infusion Access Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
MET Crusaders
Multiple Sclerosis Foundation
National Bleeding Disorders Foundation
National Eczema Association
National Infusion Center Association (NICA)
National Psoriasis Foundation
Neuropathy Action Foundation
Partnership to Improve Patient Care
Patients Rising
PD-L1 Amplifieds
Rare Access Action Project (RAAP)
The AIDS Institute
The ALS Association
The Bonnell Foundation: Living with cystic fibrosis
Vasculitis Foundation

Enclosure: [EACH/PIC Coalition Patient Affordability and Access Survey](#)