



Mailing Address:

Attn: Jen Laws
PO Box 3009
Slidell, LA 70459

Chief Executive Officer:

Jen Laws
Phone: (313) 333-8534
Fax: (646) 786-3825
Email: jen@tiicann.org

Board of Directors:

Darnell Lewis, Chair
Riley Johnson, Secretary
Dusty Garner, Treasurer

Michelle Anderson
Hon. Donna Christensen, MD
Kathie Hiers
Kim Molnar
Judith Montenegro
Amanda Pratter
Trelvis D. Randolph, Esq
Cindy Snyder

Director Emeritus:

William E. Arnold (*in Memoriam*)
Jeff Coudriet (*in Memoriam*)
Hon. Maurice Hinchey, MC (*in Memoriam*)
Gary R. Rose, JD (*in Memoriam*)

National Programs:

340B Action Center
PDAB Action Center
Transgender Leadership in HIV Advocacy
HIV/HCV Co-Infection Watch

National Groups:

Hepatitis Education, Advocacy & Leadership
(HEAL) Group
Industry Advisory Group (IAG)
National ADAP Working Group (NAWG)

April 9, 2025

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

RE: Cost Investigation and Data Validation

Dear Honorable Members of the Colorado Prescription Drug Affordability Board,

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions. State Prescription Drug Affordability Boards are of profound importance to our community.

Today, we write with concerns regarding cost evaluation and data validation efforts.

Budget Impacts Have Still Not Been Examined

Given the delays in the commencement of rulemaking proceedings in the setting of a UPL, we are concerned that staff has yet to investigate costs effectively. In the steps leading up to the affordability reviews that deemed Enbrel unaffordable for Coloradans, many different cost metrics related to drug pricing were examined from multiple viewpoints. Statute-defined factors to be used to set a UPL also discuss many different pricing factors such as carrier paid amounts and public healthcare fee schedules. However, there has not been equal thoroughness in evaluating the implementation costs, either direct or indirect.

RE: Cost Investigation and Data Validation

April 9, 2025

Page Two

Implementation of a UPL for one or multiple drugs requires additional labor utilization to monitor and ensure compliance, process required reporting by affected plans, and solicit and analyze data generated regarding the outcomes of UPL setting. Moreover, as evidenced by Orgeon's cost research conducted by an independent consulting group, a UPL can result in costs to the state Medicaid program and safety-net entities due to lost revenue. Although Oregon has not instituted a UPL, they sufficiently completed an analysis that indicated additional adverse costs to the state coupled with meager savings that did not warrant the potential for access challenges and the fiscal instability of finances associated with the state budget.

Effective consulting with state entities already in existence can facilitate an accurate picture of the true costs of a UPL on one or many drugs without a de novo data undertaking. Cost does not just pertain to the price of drugs but applies to the financial effects of implementation for patients and multiple stakeholders. One cannot explore actions to take regarding setting drug pricing, assuming that things will work out while ignoring the fiscal ramifications of cost-setting. Moreover, without a budgetary target of desired savings in any form, it is impossible to forecast if the desired savings can be achieved when all necessary costs are not accounted for.

We would encourage more substantive cost investigation to be undertaken, especially with data already readily available, such as staffing and consulting costs and additional appropriations needed to shore up lost funding as a result of a UPL of one drug or many, before attempting to set a UPL for one or more drugs.

Data Validation Starts with a Flawed Foundation

Agenda items for the April meeting include APCD data validation overviews for Enbrel, Cosentyx, and Stelara. It is important to note that regarding data validation, we are concerned that the foundation of any affordability discourse remains fatally flawed. During the affordability review phase, the Board did not ensure clean and applicable data acquisition since the Board did not ensure patient survey responses were Colorado-specific. The survey solicitations were across multiple states. This does not coincide with Board statutory directives or limitations of Colorado law. Additionally, there was no verification that the respondents were **not** Medicare beneficiaries. The experiences of Medicare beneficiaries are valuable. However, assessments of "affordability" and the implementation of cost-containment activities cannot include Medicare data, given that the state of Colorado cannot enact a UPL on Medicare claims.

APCD Data is Insufficient

APCD data does not consider claims denials or utilization management. Both increase patient and system costs financially and in regard to the effort required to navigate the processes associated with denials and utilization management. Dealing with both can be adversely burdensome to patients and caregivers, resulting in suboptimal care, including treatment abandonment, which is not reflected in APCD metrics.

The last meeting briefly touched on the desire to include some sort of denial and utilization management inquiry in the data submission guide. However, that guide has not yet been finalized.

Lastly, Board affordability discourse surrounding UPLs and supply chain elements has had a substantial focus on various aspects of drug rebates. A [recent communication issued by the Center for Improving Value in Healthcare](#) (CIVHC) analyzes drug rebate data for Colorado's top 15 most commonly rebated drugs. It is crucial to note CIVHC explains that in spite of rebates, drug costs for patients and payers continue to

RE: Cost Investigation and Data Validation
April 9, 2025
Page Three

increase. Proper affordability data analysis requires detailed, fully explanatory, properly filtered, and documented data. Without robust and properly informed data, including the multifocal costs of implementing policies, there is the risk of misinterpretation of data to support a pre-determined conclusion.

Respectfully submitted,



Ranier Simons
Director of State Policy, PDABs
Community Access National Network (CANN)

On behalf of
Jen Laws
President & CEO
Community Access National Network