COMMUNITY ACCESS NATIONAL NETWORK

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Submitted for Public Comment: Colorado Prescription Drug Affordability Board Meeting, February 16, 2024

February 15, 2024
Colorado Prescription Drug Affordability Board
Colorado Division of Insurance
1560 Broadway, Suite 850
Denver, CO 80202

Madam Chair and Honorable Members of the Colorado Prescription Drug Affordability Board,

Community Access National Network once again wishes to express our grave concerns regarding the Board's selection of Genvoya for "affordability review".

As an engaged patient stakeholder group, we appreciate the work staff did in drafting the "affordability review". However, important context is missing from the content of the report which reflects not only the need for timely, personalized medication selection for people living with HIV but also with regard to the public health safety net and overall "systems costs" impacts. We also wish to point out the shifting "concern" rhetoric expressed by Board and PDAAC members in contradiction to the legislative record and the purpose of the PDAB activities and goals.

First, according to the "affordability review" report, only 22 patient stakeholders responded to surveys attempting to gain insight into patient "affordability". This amounts to about 2.5% of patients utilizing Genvoya in Colorado. The Board and staff was made aware their efforts to reach patient stakeholders repeatedly throughout the survey period were insufficient both in terms of time and collaboration with existing state agencies already in connections with affected communities and providers. Public comments and private meetings explained to staff and the Board that in order to increase engagement from both patients and medical providers, staff would need to cooperatively work with the Colorado Department of Public Health and Environment. To our knowledge, this outreach to collaborate in engagement occurred within less than a week of the initial closing period of the survey and only via one email listserv distribution by the state health department. Evidence of the insufficient nature of the Board's outreach efforts can be found in that despite opening a second survey period, surveys received **NO ADDITIONAL RESPONSES**. This is despite patient community efforts to collect additional responses from across the nation (as advertised by The AIDS Institute and on national listservs like the Federal AIDS Policy Partnership).

Results from survey responses found only 2 had out of pocket costs in the $50-$100 range with one patient saying cost does "NOT" affect access. No knowledge was gleaned on the other patient's qualification for assistance programs,

navigation assistance, nor provider or pharmacist involvement in assisting the patient in accessing the medication. Indeed, despite this lack of specified questioning distinguishing other care costs, patient responses noted some of these in detail. The survey did not ask about formulary priority and how such designation affected patient affordability. No respondents reported having out of pockets costs above $100. Manufacturer assistance programs bring the patient out of pocket cost to $0-$5.

Indeed, given these responses, staff noted in the December 8th review of the draft report (at ~2:29), that Genvoya was "very similar to Trikafta in terms of listening to what patients have told us about the assistance programs that are available." This was in reference to a Board member asking about the state's AIDS Drug Assistance Program (ADAP – in Colorado SDAP) offering funding assistance. To be clear, while Genvoya is also accessible via manufacturer patient assistance programs, the state's participation in the Federally funded AIDS Drug Assistance Program is not the same. Addressing previous concerns from Board members, particularly the Chair, accessibility via ADAPs is not subject to manufacturer decisions. Equating the Federally funded program with manufacturer assistance program is flawed. Financially eligible patients will *always* have access to the program, as it is administered by the state of Colorado, rather than any private interest.

This leads to the issue of "system" cost by way of government-funded programs. Not noted in the report, one of the attending participants for the small group meetings included former SDAP Director, Todd Grove. Mr. Gove offered insights as to funding mechanisms in the 340B program as a pillar of financial support and extending access to care for people living with HIV. While an upper payment limit would not affect the purchase price of a 340B drug, it would potentially dramatically decrease the rebate value and the program's ability to re-invest those savings into serving other patients. Mr. Grove was adamant about the very simple conclusion: implementing an upper payment limit would pose a threat to the stability of the SDAP.

Similarly, patient advocates and providers attending the same meeting explained that 340B rebates are also utilized by safety net providers such as Federally Qualified Health Centers (FQHCs) and certain non-profit hospitals, which serve as important providers for impoverished and marginalized communities – the very communities this Board has stated to have a priority in serving. A reduction in 340B rebate value would, similar to the SDAP, pose the potential to dramatically reduce these safety net providers' ability to serve their communities. The cost in imposing an upper payment limit is higher than any theorized "savings", of which **none** are mandated to be passed back to patients or plan sponsors, such as the State of Colorado.

Lastly, both provider and patient participants within this meeting emphasized the dynamics of effective patient engagement, personalized, timely care in meeting the health outcomes goals patients have, achieving success in public health initiatives to End the HIV Epidemic, and in reducing overall "costs to system". Indeed, many survey responses stated Genvoya helps patients avoid hospitalization – a dramatically steeper cost than the medication itself – also a fact pointed out during the stakeholder engagement session.

> ***"… it's a lot less expensive than three weeks in intensive care. So anything we can do to keep people from hospitalizations is also cost savings and humane."***

CANN appreciates the well-meaning intention of legislators, staff serving the Board, and Board members themselves. However, the data available, complexity of the drug supply chain, and the variety of factors impacting reimbursement limits will not change the following facts:

1) Genvoya is both affordable and accessible, both to individual patients and the State of Colorado's health system writ large. Imposing an upper payment, in fact, would pose a viability threat to safety net providers across the state and negatively impact patient access to care – in direct opposition to the public health goals of the state.

2) An upper payment limit provides no meaningful relief to the issues of cost for either patients or "the system". Regardless of the medication selected for review, the same issues will remain. Lacking a mandate for "savings pass-through" to patients or plan sponsors, the only tool provided to the Board is simply ineffective in addressing the concerns of the legislature.

CANN urges the Board to ensure continued access to Genvoya by acknowledging the data in front of us all and deeming Genvoya "not unaffordable".

CANN also joins our shared patient community groups in urging the Board to recognize the flaws of an "upper payment limit" only approach to addressing serious concerns of patient access to care. The Board is provided the opportunity to educate the legislature as to findings and challenges via annual report. The Board would better serve the public interest and its own goals by ceasing all "affordability reviews" and proceeding with legislative report activities.

Respectfully,

Jen Laws
President & CEO