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

Dear Members of Colorado Prescription Drug Affordability Advisory Council,

Members of the Council,

Thank you for all your hard work on a very difficult issue. Drug affordability impacts all of us, and could become a bigger issue over the next decade. Colorado has gone through its first affordability reviews and is working on upper payment limits for 3 medications. This gives us some time to fix snafoos and concerns surrounding the process before moving on to new drugs. As a person living with some common and not-so-common illnesses, I'm hoping we can work together and improve patient, provider, and caregiver outreach. In addition, I'd love to see improvements in data collection, analysis, standardized procedures for evaluating medication, and making sure patients are protected from losing access to a working therapy.

- **We would like to see the PDAAC assets utilized in a more productive manner.** There is a wealth of knowledge in the PDAAC that could be better harnessed to help make sure that the patient needing each drug is kept in focus.
- **Patient, caregiver, and provider engagement needs to be a priority.** Participation in stakeholder groups was exceptionally low, despite the reopening of surveys. Going forward, the Division of Insurance is encouraged to utilize social media platforms, develop partnerships with local hospital systems and pharmacies for engagement, and maximize awareness of opportunities to engage. Clearly, posting on the website was not enough to get the engagement levels needed for accurate affordability data. This measure was passed to help patients afford critical medications, so data from patients with lived experiences, their caregivers, and providers is crucial to success.
- **Drugs for rare diseases, those without therapeutic alternatives, and orphan drugs need to be excluded for selection until you have solid data that a UPL won't interrupt or halt live-saving treatment.** As you all know, the Prescription Drug Affordability Drug reviewed Trikafta, a miracle drug for patients with a specific type of cystic fibrosis. This review caused extreme fear and upset in Colorado's small cystic fibrosis community. The Board failed to recognize this has no alternative, and went through the entire affordability process. These types of drugs should be automatically excluded from the review process. It is

not okay to experiment with the lives of rare disease patients, many of whom have ***no other therapy option***.

- **There is no process for waiving the UPL for those who cannot use any other medication.** Alternative therapies and biosimilars are not interchangeable for most chronic illnesses. Each medication works in a specific way, and biosimilar drugs are just that - similar. There is strong evidence to suggest that upper payment limits will impact formularies and access. The PDAB and Division of Insurance has not created a process where patients can seek relief from the UPL should it interfere with access to their working therapy.
- **The Board has no voting patient representation on the Board and we are tired of being told we don't have the capacity to learn anything outside our own disease area.** We understand the Board feels patients would not be able to comprehend information outside their specific conditions, but we disagree. You all are learning as you go and a patient is just as capable of doing the same. There have been several times it's appeared that you all don't have a full grasp on what impacts the UPL will have, with multiple comments being made about helping uninsured and Medicare. You've also mistakenly suggested Trikafta had therapeutic alternatives. You've learned as the process has progressed, and a patient is just as capable as you of doing the same thing. We bring a perspective you cannot have unless you are in our shoes and could help make sure that our experiences are at the forefront of each decision.
- **The affordability review process was plagued with multiple concerns with data and its collection.** Several issues with the patient/caregiver surveys have been raised, there were errors in the All Payer Claims Data used, and the Board has shown serious bias to which feedback weighs the most. These open biases have cast a huge shadow over the work and intentions of this Board. Until a more comprehensive survey with context is created, community outreach is significantly increased, and data (including financial) is more appropriate and transparent, the Board's work lacks credibility.
- **We would like to see the PDAAC and PDAB get more involved with suggestions to the legislature about policies that will directly impact patient out of pocket costs and generate real savings on premiums like enforcement of accumulator programs, banning maximizer programs, Prescription Benefit Manager reforms, incentives for "pass through PBMs", and insurance plan design reform.** The Board has chosen to only look at upper payment limits despite statute saying they can make recommendations to the legislature about healthcare policy. We've asked for their help to advocate for real a affordability measures but they've claimed the only suggestions they can make are around upper payment limits. We would hope that they'd encourage other methodologies, but have declined to be a voice for prescription affordability as a whole. We'd like to see that change. Other PDABs like Oregon, are utilizing a more holistic approach and getting involved in a much broader way.

Colorado should take note.

We look forward to working with the PDAAC to help make sure the needs of Colorado patients are not overlooked.

Sincerely,

Bridget Dandaraw-Seritt