

DAFNA MICHAELSON JENET

State Senator
200 E. Colfax Avenue
Denver, Colorado 80203
Capitol: (303) 866-4878



COMMITTEES

September 27, 2023

Dear Members of the Colorado Prescription Drug Affordability Board,

We, the undersigned legislators, are writing to strongly urge you not to proceed with the imposition of an upper payment limit for the cystic fibrosis treatment Trikafta.

We appreciate and believe in the important work that the PDAB is doing to address the high costs of prescription medications and agree that the governor specifically appointed experts in their fields who would understand how drugs impact lives. We are simply writing to seek clarity regarding the specific reasons for the PDAB's decision to consider an orphan drug, despite the authorizing legislation's emphasis that the Board take into account recommendations from the Prescription Drug Affordability Advisory Council as well as factors such as orphan drug status, patient out of pocket cost, overall changes in price, patient count, and significant input from patients themselves.

Orphan drugs play a crucial role in treating rare diseases. These medications are developed to address unmet medical needs within small patient populations. The General Assembly had substantive discussion and debate during the passage of the enacting legislation, which made clear these particular types of drugs have a unique and life-altering impact for the patients who rely on them. Since then, we have learned more about these critical medicines, as well as heard from constituents and stakeholders across the state who have significant concerns about the PDAB process and the selection of Trikafta for an affordability review, despite the Advisory Council recommendation that rare disease drugs not be reviewed in the first year due to the unknown impact of an upper payment limit on patient access.

We have heard from stakeholders who have been unable to follow the process and are deeply concerned their voices are not being adequately considered despite significant and extensive public comment. Patients with cystic fibrosis have reached out to their legislators with personal testimony concerning the importance of Trikafta in their lives. We feel that it is important for board members to hear these testimonies directly.

We appreciate the complexity of the issues surrounding drug pricing and affordability. However, it is critical the PDAB takes a balanced approach to this important work that considers the

feedback of Coloradans most impacted by changes to the market for rare disease drugs. **We kindly request the Colorado Prescription Drug Affordability Board pause any review of Trikafta in order to provide a prompt response to this letter in advance of the next Prescription Drug Affordability Advisory Council Meeting scheduled for October 12, 2023.**

We encourage the board to follow the requirements of the law and to include in their decision making at this stage whether a drug is a sole orphan drug and how it impacts patients' lives. We believe open dialogue and collaboration will lead to solutions benefiting both patients and the broader community, and is preferable to the legislature taking future actions clarifying our intent.

Thank you for your attention to this matter and we look forward to your response.

Sincerely,

Senator Dafna Michaelson Jenet
Representative Rod Bockenfeld
Senator Rachel Zenzinger
Senator Janet Buckner
Senator Rhonda Fields
Representative Iman Jodeh
Representative Judy Amabile
Representative Lindsey Daugherty
Representative Sheila Lieder
Representative Matt Soper
Representative David Ortiz
Representative Mary Young
Representative Barbara Kirkmeyer
Senator Janice Rich
Senator Joann Ginal
Representative Anthony Hartsook
Representative Regina English
Senator Perry Will
Representative Mary Bradfield

CC:

- Colorado Prescription Drug Affordability Advisory Council
- Governor Jared Polis, State of Colorado
- Commissioner Mike Conway, Department of Insurance, State of Colorado ● Alec Garnett , Office of the Governor, State of Colorado
- David Oppenheim, Office of the Governor, State of Colorado
- Allie Kimmel, Office of the Governor, State of Colorado