BOOMER ESIASON FOUNDATION

August 3, 2023

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

Dear Members of the Colorado Prescription Drug Affordability Review Board,

We write on behalf of the Colorado cystic fibrosis (CF) community, and as members of the broader CF community. One of us (GE) is 32 living with CF while the other (BE) is a CF parent. Together we have watched this god-awful disease end lives far too early, crush dreams, and unleash unspeakable horrors on those who suffer from CF. But we have also seen, and lived through, what we consider to be among the best stories in medicine – that is the powerful effect TRIKAFTA has had on thousands of CF patients across the country and the hundreds living in Colorado.

Gunnar was effectively living on the precipice of end-stage disease when he enrolled in the clinical trial that resulted in TRIKAFTA's historically fast FDA approval. Today, some five years later, he no longer suffers from the worst parts of CF and, in fact, has become a father himself. Gunnar's story is not unique. We have seen this story play out over, and over again across the community. In fact, the CF community at large is experiencing a baby-boom thanks to this medical progress. Is that not precisely the reason we, as a society, pursue pharmaceutical interventions for otherwise life shortening conditions?

Together, we are deeply disturbed to see TRIKAFTA on the prioritized list for review, which we feel may jeopardize access to the drug for some hundreds of patients living with CF in Colorado. We cannot help but conclude that the Board's motivation to question one of the most successful breakthroughs of the modern era is political in nature. Moreover, we question if the Board's perspective is that society ought to be anti-pharma instead of pro-patient? The Board's actions leave no room for any other conclusion, and we find that to be a dangerous path to tread.

Specifically, we take issue with Board's frameworks that overlook cystic fibrosis as a rare disease, and further the failure to consider the long-term value TRIKAFTA offers as a small molecule medication.

First, to judge TRIKAFTA on the medicine's cost per-patient per-year is a direct attack on rare disease communities across Colorado. Rare disease drugs lack sales volume, which necessitates high launch prices before their inevitable exclusivity cliff. We feel as though it is the payor community's responsibility to bear the cost of keeping terminally ill children and young adults alive in exchange for the drug manufacturer's enormously costly drug development cycle. The board must not hold these economic realities against those born into this disease. Furthermore, it would signal that rare disease drug manufacturers should be weary of Colorado's misguided policies.

We point to TRIKAFTA's high access rate for eligible patients as evidence of the market functioning as it should within this rare disease community.

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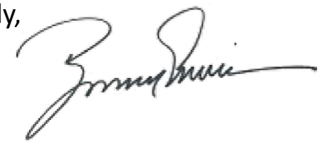
Second, TRIKAFTA's list price will not be high in perpetuity. The drug manufacturer will lose its exclusive place as the drug's only seller. In due time, TRIKAFTA will go generic, and when it does, society will reap one of the key benefits of small molecule medicines: its high price tag will evaporate. Future generations of CF patients both inside Colorado and across the globe will continue to enjoy the highly efficacious nature of both TRIKAFTA and future generic copies, while state and commercial payors will manage cystic fibrosis care at a fraction of today's cost. By only considering TRIKAFTA's price tag today, the Board will do an injustice to the drug's long-term value proposition.

Taken together, these two points constitute the symbiotic relationship between drug makers and payors that patients, like Gunnar, rely upon. Should the Board take price controlling actions on TRIKAFTA, it risks upsetting this balance long before the drug is due to face its exclusivity cliff and could result in patients paying the price for it.

TRIKAFTA is precisely the kind of medicine our pharmaceutical industry should be developing. Any action to meddle in a functioning market that has delivered a medication like TRIKAFTA is, in our view, a misguided policy and represents a threat to future drug development, especially for rare diseases.

Colorado is a beacon for CF care across the world with its renown cystic fibrosis care centers – where Gunnar once received care for an illness he suffered during his childhood. We can't imagine a world where Colorado's state government leaves CF patients experiencing a gap in their care. We implore the Board to consider the value TRIKAFTA provides to the patients who need it, the families who care for them, and the society and economy in which they live – both today and in the future.

Respectfully,



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CC: Members of the Colorado Prescription Drug Affordability Review Board

About the Boomer Esiason Foundation

In 1993, Gunnar Esiason – son of former NFL MVP quarterback Boomer Esiason – was diagnosed with cystic fibrosis. Boomer and his wife Cheryl founded the Boomer Esiason Foundation to raise funds and awareness for the cystic fibrosis community. The Foundation has raised over $150 million to date. The Foundation provides financial assistance to people with cystic fibrosis through academic scholarships, emergency relief funds, and In-Vitro Fertilization (IVF) grants in addition to contributing resources to cystic fibrosis care centers and the research for a cure. To learn more, visit esiason.org.

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