BOOMER ESIASON FOUNDATION

March 14, 2024

Committee on Human Services
Connecticut General Assembly
Legislative Office Building
300 Capitol Avenue
Hartford, CT 06106

Dear Honorable Members of the Committee on Human Services:

On behalf of the Connecticut cystic fibrosis (CF) community, and as members of the broader CF community, we are concerned at the Committee on Human Services' consideration to implement a Prescription Drug Affordability Review Board (PDAB) through Connecticut Bill SB00008 – AAC Drug Affordability. Cystic fibrosis (CF) is a chronic, life-threatening genetic condition that affects primarily the lungs and digestive system. CF affects about 40,000 people in the United States and many of whom live in Connecticut. The Boomer Esiason Foundation works to spread awareness and raise support for people living with CF and their families. Healthcare affordability and accessibility are cornerstones of our organization's advocacy work and we understand the Committee on Human Services' desire to address these important issues. However, a PDAB is a misguided policy that does not address the true levers of affordability that govern healthcare costs for Americans, which are out-of-pocket costs. Out-of-pocket costs are not only unfair, but hurt patients in the long-run. Small increases in out-of-pocket costs can lead to negative health outcomes and even death for patients. Eliminating out-of-pocket costs can meaningfully lower healthcare spending without compromising patients' access to lifesaving medications and overall wellbeing.

As seen in other states, we fear that PDABs meddle with the functioning drug market, which can stifle drug development and threaten patients' access to lifesaving medications.

We write knowing that PDABs often exploit drug price sticker shock**. A drug's list price does not accurately reflect its affordability and accessibility**. Take, for example, TRIKAFTA, the rare disease drug that has drastically improved the health outcomes of 90% of the CF community. The medication has a high cost-per-patient per year, but has a high access rate for eligible patients because of the widespread availability of copay assistance and acknowledgement from the payor market that the drug is not only worth covering, but also worth making affordable. TRIKAFTA also reduces broader healthcare utilization and long-term costs for patients. One analysis shows that TRIKAFTA is cost-effective when factoring in drug market realities like genericization, pharmaceutical rebates, and benefits to caregivers.

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 Connecticut and across the globe will continue to

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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, PDABs do an injustice to the drug's long-term value proposition.

This is evidence of the market functioning as it should within this rare disease community.

In December of last year, the Colorado PDAB determined that TRIKAFTA is widely accessible and therefore not unaffordable. This decision came after passionate advocacy from the CF community, which we would expect to follow in any state that risks jeopardizing access to essential medication.

It's not clear to us that PDABs are effective and appropriate adjudicators of affordability within the prescription drug market given the subjectivity of the assessments they perform and the potential for a patchwork of reimbursement and access policies across the nation. Ultimately, we question the intend purpose of PDABs broadly.

We feel as though Connecticut is wading into a policy territory that potentially poses an unintended risk to patient access and could even signal to rare disease drug manufacturers that they should be wary of Connecticut's policies.

Candidly, together that is a risk our community is unwilling to accept, and furthermore is one that we hope policymakers should not be willing to levy against patients living with rare terminal diseases.

Respectfully,

Boomer Esiason
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