

United States Senate

WASHINGTON, DC 20510

December 19, 2017

Mr. Matthew Pauls
Chief Executive Officer
Strongbridge Biopharma
900 Northbrook Drive, Suite 200
Trevose, PA 19053

Dear Mr. Pauls,

We are writing to express our deep concern regarding the dramatic price increase for Keveyis, formerly known as Daranide, after Strongbridge Biopharma acquired the drug.

This drug (dichlorphenamide) was approved in the U.S. in 1958. Keveyis is used to treat glaucoma as well as a type of rare genetic disease, known as periodic paralysis, which causes attacks of muscle weakness or loss of muscle movement.¹ Some people with this condition suffer daily attacks for hours on end and these attacks can occur without warning.

As recently as the early 2000s, patients could obtain 100 pills of dichlorphenamide at a list price of \$50.² Yet, after a series of companies bought and sold the rights to this decades-old drug and obtained a new rare disease designation from the Food and Drug Administration (FDA), the list price increased to \$13,650 for 100 pills in 2015. Strongbridge recently acquired the drug and hiked the price even further to \$15,001. According to Strongbridge, patients might pay up to \$219,000 a year for this medication.³

A 300-fold increase in the cost of a vital, decades-old treatment is unacceptable. Last year, the Senate Aging Committee released a report following a bipartisan investigation into sudden price spikes in decades-old drugs, uncovering a business model that exploits market failures at the expense of patients. We are committed to combatting sudden astronomical price increases as well as any anticompetitive conduct and attempts to game the regulatory process at the expense of Americans in need of life-saving therapies.

We urge you to take immediate steps to alleviate the burden your price increases have imposed on patients and to ensure your company's behavior fully complies with relevant laws, regulations and guidance. Please provide our offices with a written response including any analysis used by Strongbridge Biopharma relating to the pricing or market share of dichlorphenamide since 2015,

¹ <https://rarediseases.info.nih.gov/diseases/6729/hypokalemic-periodic-paralysis>

² https://www.washingtonpost.com/news/wonk/wp/2017/12/18/this-old-drug-was-free-now-its-109500-a-year/?utm_term=.5ef0c56c33ef

³ https://www.washingtonpost.com/news/wonk/wp/2017/12/18/this-old-drug-was-free-now-its-109500-a-year/?utm_term=.5ef0c56c33ef

any research and development and product improvement activities Strongbridge Biopharma has conducted since acquiring this drug, and any information reviewed or generated by the Strongbridge Biopharma Board of Directors relating to the drug over that same period. Please also provide any documents examining the impact of the price increase on people with periodic paralysis and other conditions treated by this drug. We also ask that you provide a briefing to our staff at a mutually convenient time no later than three weeks from today.

We appreciate your prompt attention to this matter. Should you have any questions, please do not hesitate to contact Jordan Grossman at Jordan_Grossman@klobuchar.senate.gov, Sarah Khasawinah at Sarah_Khasawinah@aging.senate.gov, or Kathleen Laird at Kathleen_Laird@baldwin.senate.gov.

Sincerely,



AMY KLOBUCHAR
United States Senator



SUSAN COLLINS
United States Senator



TAMMY BALDWIN
United States Senator