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RE: LD 1829, Amending existing PDAB to include setting Upper Payment Limits
Date: January 31, 2024
From: Laura Bonnell, The Bonnell Foundation: Living with cystic fibrosis

Dear Members of the Health Coverage, Insurance, and Financial Services (HCIFS) Committee,

As rare disease advocate and caregiver (my daughters have cystic fibrosis), The Bonnell Foundation (which represents people in Maine) is asking you to reject policy proposals that could negatively impact the ongoing research to find much needed cures that give our families hope for the future.

We recently learned you're considering amending the current Prescription Drug Affordability Board (PDAB) LD 1829) legislation to include an Upper Payment Limit. States that have passed similar policies have found there is a lot of bureaucracy, nothing new to uncover, and very little to show for patients. In fact, it could harm patients. Law makers in Colorado found this to be true. Colorado Senator Barbara Kirkmeyer is leading the charge there to get rare disease drugs off the list of consideration by the Colorado PDAB Board.

While we believe lawmakers' intent is to help patients, the reality is that these Boards can have unintended consequences for patients and people with disabilities. Lower prices sound sexy. We have seen in other states that when similar legislation is passed without adequate patient protections – like a clear ban on the Quality-Adjusted Life Year measures, or Board seats for patient representatives – the Boards end up harming patient access to needed treatments. They may even wind up using discriminatory and biased assessments of treatment value by selecting treatments subject to a payment limit – not a doctor's expertise or what's in the best interest of her patient.

The Community Oncology Alliance stated, "a Prescription Drug Affordability Board can restrict patient access to certain lifesaving medications…" For the rare disease community this is

particularly dangerous. While we have seen strong innovation there is much more to be done as many conditions have only one treatment and still thousands more, have none.

Across the country, thousands of families like ours await breakthroughs and new developments for treatments that can extend and improve the lives of those living with rare diseases such as hemophilia, sickle cell and cystic fibrosis.

Over the past decade, the percentage of novel drug approvals to treat rare diseases has soared from 33% in 2012 to 54% in 2022. Breakthrough treatments have extended the lives of people living with rare disease so now we have a generation of kids who are reaching adulthood and able to have families of their own. We can't let short-sighted policies that do little to reduce costs for patients hinder medical progress.

Years of research and billions of dollars are poured into the process of discovering each new medicine. There are significant costs associated with clinical trials and regulatory reviews. Due to the nature of science and innovation, 90% of drug candidates fail. Companies take on an extraordinary amount of financial risk to find breakthroughs needed for just a small population of patients.

We understand this leads to higher initial prices, but those drop exponentially when the treatment becomes generic. They also save insurers in the long run by keeping people healthier and out of the hospital.

At the outset, we expect all members in the healthcare system, including insurers and Primary Benefit Managers (PBMs), to do their part to make these life changing treatments affordable and accessible instead of finding new ways to profit at the expense of the patient.

Focusing solely on pharmaceutical innovators in this proposed legislation is in direct competition with the policies our society has built over decades that have advanced medical research for the 1 in 10 patients with a rare disease who have no treatment or cure.

A Prescription Drug Affordability Board offers a one-size-fits-all approach. It especially leaves those of us with rare diseases without a voice or a choice (especially if there is an Upper Payment Limit). That's a bad policy - a policy that professes to fix something for us yet doesn't consider our true needs.

We never know where the next treatment or cure will come from. And when our families live each day at the mercy of science, we can't afford to stand in the way of new discoveries.

When considering legislation, we respectfully request you look to build a better future for all the people of Maine. There are many of us living with hope for a cure from chronic and rare diseases. The next new drug could save someone we love.

Sincerely,

Laura Bonnell, CEO
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