CYSTIC FIBROSIS FOUNDATION®

January 17, 2024

Vermont House of Representatives
Vermont State House
115 State Street
Montpelier, VT 05633-5301

Dear Honorable Members of the Vermont House of Representatives Committee on Health Care,

On behalf of the nearly 150 people living with cystic fibrosis (CF) in Vermont, we write to express our support for H 766, which makes several important reforms to the prior authorization (PA) process and requires insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements. PAs can delay access to critical CF therapies and the Cystic Fibrosis Foundation supports efforts to minimize the administrative burden PAs impose on patients and their providers and ensure access to therapies for people living with CF in the Vermont. Additionally, while copay assistance is not a silver bullet for addressing patient affordability, solutions to address drug pricing cannot come at the expense of patients' health and financial wellbeing—therefore we also support copay accumulator bans. We ask for your support of H 766.

About Cystic Fibrosis
Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. CF care is grounded in evidence-based clinical guidelines and as a complex, multi-system disease without a cure, CF requires an intensive treatment regimen including multiple medications. For people with CF, it is not uncommon to take seven therapies every day, and as many as twenty.[1] Many medications are taken year after year, and in most cases, for life. While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier for many people with the disease.

Prior Authorization Reform
Prior authorizations are one of the obstacles people with CF must navigate when accessing care. These requirements can delay the start or continuation of needed treatments, which can lead to adverse health outcomes. In a 2022 survey by the American Medical Association, 94 percent of physicians reported that prior authorizations led to delays in necessary care for their patients whose treatment required PA and 80 percent reported that PAs have led to patients abandoning their treatment at some point. Because CF is a progressive disease, patients who delay or forgo treatment—even for as little as a few days—face increased risk of lung exacerbations, costly hospitalizations, and potentially irreversible lung damage.

PAs can also cause significant administrative burden for CF providers and are often redundant for medications that people with CF must take indefinitely to maintain their health. In a CF Foundation survey of CF care teams, 58 percent of providers reported spending 20 percent or more of their time on PAs in 2016. This arduous process diverts valuable time and resources away from direct patient care.

The Foundation understands that payers adopt prior authorization policies to ensure patients only receive medically necessary care, and we recognize the challenge insurers face in managing medication utilization

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2680350/

and cost. However, utilization management cannot come at the expense of delays in patient access to needed care. H 766 provides an opportunity to make prior authorization processes more efficient, allowing for timely access to appropriate treatments. We appreciate Vermont's attention to this issue and support the following provisions in H 766:

Length of Treatment PAs
Recognizing that people living with CF and other lifelong, chronic diseases take the same drugs for most of their lives, we appreciate that H 766 requires that prior authorization approvals be valid for the duration of a course of treatment or one year, whichever is longer. Eliminating unnecessary repeat authorizations will help promote immediate and consistent access to life-saving therapies for people with CF, and significantly reduce administrative burden for CF care teams.

Exemptions for Certain Services
To further reduce administrative burden and delays in care, H766 exempts a service from prior authorization requirements if it has low variation across providers and denial rates are less than 10 percent across carriers. We support the concept of eliminating PAs for services with high approval rates and ask that the legislature further clarify the low variation requirement. Because cystic fibrosis requires highly specialized care and treatment, most people with CF receive care at a CF Foundation-accredited care center, which provide quality, specialized CF care that is based in clinical guidelines. If a medication or treatment for people with CF was exempted from prior authorization requirements, care teams could spend more time on patient care instead of paperwork and, most importantly, people with CF could avoid delays in care.

Response Times and Continuity of Care
H 766 requires health plans to respond to urgent prior authorization requests within 24 hours, thereby ensuring timely access to emergency treatments. The Foundation asks the legislature to amend the requirements for insurers to respond to non-urgent requests to within 48 hours to reflect model legislation prepared by the American Medical Association.[2] Also included in the bill is a continuity of care provision that protects patients from experiencing care delays when there are changes in coverage or when patients switch health plans. Gaps in therapy put people with CF at increased risk of costly hospitalizations and negative health outcomes. We support efforts to reduce delays in care and ensure people have timely access to their necessary medications.

Copay Accumulator Ban
H 766 would ban accumulator programs, which prevent third-party payments from counting towards deductibles and out-of-pocket limits. These programs increase out-of-pocket costs for patients and can cause people with CF to forgo needed care and lead to adverse health outcomes. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether due to cost concerns.[3] Because CF is a progressive disease, patients who delay or forgo treatment—even for as little as a few days—face increased risk of lung exacerbations, costly hospitalizations, and potentially irreversible lung damage.[4]

Accumulator programs also place additional financial strain on people with CF who are already struggling to afford their care. More than 70 percent of survey respondents indicated that paying for

[2] https://fixpriorauth.org/sites/default/files/2023-04/Health-Plans_Ensuring-Transparency-in-Prior-Authorization-Act-2022_Model-Bill.pdf
[3] https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs
[4] Trimble AT, Donaldson SH. Ivacaftor withdrawal syndrome in cystic fibrosis patients with the G551D mutation. J Cyst Fibros. 2018 Mar;17(2): e13-e16. doi: 10.1016/j.jcf.2017.09.006. Epub 2017 Oct 24. PMID: 29079142.

health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulties paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. Additionally, while three quarters of people received some form of financial assistance in 2019 to pay for their health care, nearly half still reported problems paying for at least one CF medication or service in that same year.

Accumulators are especially challenging for a disease like CF, which has no generic options for many of the condition's vital therapies. The situation has become even more dire as a company that manufacturers CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs.

****

The Foundation understands the challenge insurers face in managing medication utilization and the rising cost of drugs. However, cost containment and utilization management strategies that further burden patients and providers are unacceptable and cannot come at the expense of delays in patient access to needed care. H 766 provides an opportunity to ease administrative and financial burdens for patients and their providers, and we ask that you support this important legislation.

Sincerely,

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation