



June 26th 2023

Group Insurance Board
c/o Board Liaison
Department of Employee Trust Funds
PO Box 7931
Madison, WI 53707

Dear Members of Wisconsin's Group Insurance Board:

On behalf of the nearly 700 people with cystic fibrosis (CF) in Wisconsin, we write to express our opposition to Navitus' Copay-Max Plus Program that the Group Insurance Board (GIB) is considering as part of proposed 2024 benefit changes for state employees and retirees. The proposed program would threaten prescription drug affordability and access for people with CF who work for or are retired from working for the state of Wisconsin. **We urge you to oppose implementation of Navitus' Copay-Max Plus Program in the 2024 state employee and retiree health plans in order to protect patients.**

We understand the challenge insurers face in managing the rising cost of drugs. However, cost containment strategies that further burden patients are unacceptable. 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 manufactures CF therapies recently reduced the amount of copay assistance available for people enrolled in accumulator programs. Patients with chronic diseases like CF often struggle to afford their care and rely on copay assistance to access vital medications. This proposal would put profits above patients' health and financial wellbeing.

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. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier to care for many people with the disease.

Accumulator programs jeopardize access to care

Accumulator programs, like the one proposed, prevent third-party payments from counting towards deductibles and out-of-pocket limits and therefore increase out-of-pocket costs for patients—which 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.¹ Because CF is a progressive

¹ https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

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.²

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 health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. And 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.

We urge you to oppose the addition of Navitus' Copay-Max Plus Program to the Department of Employee Trust Fund's 2024 Pharmacy Benefits Program and help ensure continued access to quality, specialty care for people with CF, while we all work towards longer-term solutions to address the affordability of health care in the US. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Wisconsin.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', with a stylized flourish at the end.

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

² 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.