



October 14, 2020

Commissioner Jeanne Lambrew, Ph.D.
Maine Department of Health and Human Services
109 Capitol Street
11 State House Station
Augusta, ME 04333

Dear Commissioner Lambrew,

On behalf of the 260 people in Maine living with cystic fibrosis (CF), we thank you for all that you are doing to ensure the health and safety of Maine residents in the midst of the COVID-19 pandemic. While we understand these are unprecedented times, we ask you to supplement existing funding for the Maine Children with Special Health Needs (CSHN) assistance program in the Department's request for the 2022 – 2023 biennial budget to restore previously cut services and eligibility.

About Cystic Fibrosis & the CF Foundation

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 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 access for many people with the disease. According to a recent survey conducted by the George Washington University of 2,500 people living with CF, 45 percent of people with cystic fibrosis spend \$5,000 or more annually on out-of-pocket costs for copayments, coinsurance, and non-covered services. Nearly six in ten people with CF report delaying or forgoing care due to cost concerns.

CSHN assistance program

CSHN is a state program run by the Department of Health and Human Services' (DHHS) Center for Disease Control and Prevention and funded through revenue from the state's newborn bloodspot screening test. The program, which serves as a payer of last resort for a range of services, previously helped children and adults with cystic fibrosis afford their care regardless of age, income, or insurance status. Due to budget shortages, the program scaled back eligibility and covered services, effective November 1, 2019. It ended the portion of the program serving adults with CF and restricted reimbursement to two covered services for children and their families: mileage and lodging for medical appointments, and low-protein foods and metabolic formula. The new guidelines limit eligibility for the program to families who fall below 225 percent of the federal poverty (FPL) and are uninsured, or whose insurance does not reimburse for CSHN-covered services.

Impact of changes to program guidelines

The program's updated benefits exclude the services that people with CF depend on most to access their care. According to data provided by CSHN program staff, the top five services for which enrollees with CF submitted claims in 2018 were hospitalizations and doctor's appointments, medications, durable medical

equipment and other medical supplies, mileage reimbursement, and lodging for medical appointments—three of which are no longer covered under the program’s revised benefits. Copay assistance for just two of these services—hospitalizations and medications—accounted for nearly three-quarters of the program’s total expenditure on individuals with cystic fibrosis. Without the support of CSHN, many people with CF now face gaps in coverage that cannot be filled by other sources.

From conversations with CSHN program staff, we understand that the decision to scale back benefits and eligibility was due, in part, to the existence of private organizations like the HealthWell Foundation. HealthWell, a non-profit that helps the underinsured pay for out-of-pocket costs, offers 12-month grants to people with CF whose incomes are under 500 percent FPL to cover prescription copays, and to those with incomes below 400 percent FPL to cover vitamins and supplements. While HealthWell is a useful resource for people with cystic fibrosis, it is not an adequate substitute for public programs like CSHN. HealthWell has limited funding and some recipients exhaust their grant money before their enrollment period ends. Its two CF grants are also limited to prescriptions and vitamins and supplements, respectively, even though people with CF experience high cost-sharing for a variety of services. Moreover, there is no guarantee that the organization will continue to exist indefinitely; their website currently lists dozens of disease funds that are temporarily closed to new patients due to insufficient funds.¹ We are not aware of any other private organizations in Maine that provide assistance with the full range of services previously offered by CSHN for people with CF.

Policy recommendations

We understand that the state of Maine is facing budget constraints as it works to mitigate the effects of the COVID-19 pandemic. However, recent changes to Maine’s Children with Special Health Needs assistance program’s eligibility and benefits jeopardize access to care and treatments for people with CF at a time when they need it most. The pandemic has taken a toll on family finances for so many in our community, exacerbating the challenges they already faced affording their care.

Therefore, we ask the Department to supplement the CSHN program’s existing funding in DHHS’s 2022 – 2023 budget request to restore previously cut services, remove income eligibility requirements, and reinstate the adult portion of the program. The relatively small portion of the total budget needed to adequately fund this program will go a long way to help to ensure the health and wellbeing of people with CF.

Thank you for your attention to this important issue. We look forward to working with you to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,



Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy and Advocacy

¹ [https://www.healthwellfoundation.org/disease-funds/?fund_status\[\]=closed](https://www.healthwellfoundation.org/disease-funds/?fund_status[]=closed)