



March 16, 2021

Senator Ned Claxton, Senate Chair  
Representative Michele Meyer, House Chair  
Health and Human Services Committee  
Cross Building, Room 209, 287-1317  
Augusta, ME 04330

Dear Chairman Claxton, Chairwoman Meyer, and Members of the Health and Human Services Committee:

On behalf of the 260 people with cystic fibrosis (CF) in Maine, we urge you to support LD 529, which would restore previously cut eligibility and benefits to the Maine Children with Special Health Needs (CSHN) Cystic Fibrosis Assistance Program. Changes to the program, which took effect on November 1, 2019, jeopardized access to care and treatments for people with CF at a time when they could least afford it. The pandemic has taken a toll on family finances for so many in our community, exacerbating the challenges they already faced affording their care. By supporting this bill, you will help ensure Mainers with CF have the financial support they need to access the care and treatments required to maintain their health and well-being.

***About Cystic Fibrosis***

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 George Washington University of over 1,800 people living with CF and their families, more than 70 percent of respondents said 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. Even with the help of financial assistance, nearly half of people with CF that were surveyed reported delaying or forgoing care due to cost concerns.

***CSHN Cystic Fibrosis 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.

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.

**Support LD 529**

**If passed, LD 529 would restore previously cut services, remove income requirements, and reinstate the adult portion of the CSHN Cystic Fibrosis Assistance Program. It would remove recently added eligibility requirements and re-open the program to all people with cystic fibrosis, regardless of age, income, or insurance type. LD 529 would also reestablish coverage for vital services, such as copay assistance for hospitalizations and doctor's appointments, medications and durable medical equipment, and other medical supplies. These changes will go a long way to help to ensure the health and wellbeing of people with CF.**

While the Office of Fiscal and Program Review (OFPR) estimates an annual cost of \$501,000 for LD 529, we believe restoring CSHN eligibility and services for people with CF—even after accounting for potential increases in enrollment and utilization due to the pandemic and economic recession—will require an annual appropriation far less than this estimate. According to data provided by CSHN staff, the program's total expenditures for enrollees with cystic fibrosis was \$100,110 in 2018, the last full year before the revised guidelines took effect.

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We urge you to support LD 529. By supporting this bill, you will help ensure continued access to quality, specialty care for people with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Maine.

Sincerely,

**Mary B. Dwight**

Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation  
Bethesda, MD

**Kathryn S. Rutledge, MD**

Associate Director, Affiliate CF Care Center  
Northern Light Eastern Maine Medical Center  
Bangor, ME

**Anne Coates, MD, FAAP, FCCP**

Associate Director, Pediatric CF Care Center  
Maine Medical Partners Pediatric Specialty Care  
Portland, ME

**Thomas Lever, MD**

Director, Affiliate CF Care Center  
Northern Light Eastern Maine Medical Center  
Bangor, ME

**Edmund Sears, MD**

Associate Director, Adult CF Care Center  
Maine Medical Center  
Portland, ME

**Ana M. Cairns, DO, FAAP, FACP**

Director, Pediatric CF Care Center  
Maine Medical Partners Pediatric Specialty Care  
Portland, ME

Cc: Health and Human Services Committee Members