



April 6, 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 Mainers living with cystic fibrosis (CF), we thank you for your consideration of LD 529, which would have restored vital funding and services for the Children with Special Health Needs (CSHN) CF Assistance Program. We appreciate you taking the time to hear this bill and accompanying testimony from Mainers across the CF community about the importance of the program. We understand that LD 529 has been amended to study the prevalence of low-incidence disease populations and their unmet needs; the Cystic Fibrosis Foundation stands ready to serve as a resource to this committee and the state in that effort. We also hope that there will be future opportunities to consider reinstatement of previously cut eligibility and services to the CSHN program. To that end, we write to share information that we hope will help facilitate an informed conversation on this issue moving forward.

Barriers to care for people with CF

State programs like the CSHN Assistance Program are critical safeguards for people with CF, as nearly all people with CF struggle with the cost of their care and many are forced to make difficult spending tradeoffs that can impact their health. According to a recent survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half of respondents across all ages reported problems paying for at least one health service in 2019. The same survey found that nearly half of all respondents reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, filling a prescription, or skipping a treatment altogether—due to cost concerns. Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Impact of CSHN CF Assistance Program changes

While we understand the reality of state budgets, changes to CSHN Assistance program eligibility and services that took effect in 2019 have effectively rendered the program unusable for the CF patients it was designed to serve. We were alarmed to learn in a recent conversation with Maine Center for Disease Control and Prevention staff that the program does not currently cover a single person with cystic fibrosis. For comparison, data from the state obtained via a FOIA request shows that there were 166 children and adults with CF enrolled in the program in 2018.

Funding needed to restore CSHN CF Assistance Program

We understand the committee's decision to not proceed with restoring funding to the CSHN Assistance program was based, in part, on the estimate that funding restoration would cost \$501,000 annually. From conversations with program administrators, we understand the \$501,000 estimate assumes every person

with CF enrolled in the program in 2018 would receive the maximum reimbursement amount of \$3,000 per enrollee. However, total expenditures on CF enrollees in 2018 were only \$100,100—a year in which the CSHN CF Assistance Program served both children and adults, regardless of income or insurance type. Even after accounting for a potential woodworking effect, it is unreasonable to estimate that every enrollee with CF would submit claims for the maximum allowable reimbursement, since only 89 of the 166 enrollees submitted claims in 2018. Cost estimates should be based on past expenditure data, as LD 529 was intentionally written to restore—not add or expand—previously offered eligibility and covered services.

We hope the committee will continue to keep the needs of people with CF in mind as it develops policies for those living with rare diseases. We appreciate your attention to this important issue and look forward to continuing our partnership to improve the lives of Mainers with CF.

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

Cc: Health and Human Services Committee Members