

Submission of written testimony for LD 529

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I am writing today as a social worker who has worked with patients with CF and their families and caregivers for the past 8 years. Through the past 8 years, I have had the privilege to work closely with these patients and families and have been incredibly honored to be welcomed into their lives.

Over the past 8 years, I have borne witness to the financial, emotional, and physical toll that patients with CF and their caregivers face every day. CF is an everyday diagnosis. As families and patients will be sharing today, it is a diagnosis that requires a tremendous amount of vigilance with costly daily treatments. Treatments alone can take 4 hours a day with a combination of nebulizers, airway clearance, taking an assortment of pills, and cleaning all of the necessary devices. This does not include the many phone calls to medical offices, insurance companies, pharmacies, and office visits to pulmonary clinics, GI clinics, endocrinology clinics, and other specialty clinics. Now imagine navigating all of these acute medical needs while also taking on the things that kids and families and adults must face every day- work, school, sports, family life, and so on.

CF is an expensive medical diagnosis. There are costs to get to and from appointments and copays for office visits, procedures, two week inpatient hospitalizations, medications, and equipment. Many patients and their families must consider medical costs in addition to day to day costs. I have worked with families who have had to “rob Peter to pay Paul”. They defer paying utility bills, especially electric bills in order to pay for their medical care. This inevitably puts them at risk of having their electricity shut off. Imagine the panic of facing having your electricity shut off while also knowing that you or your child relies on electricity for daily CF care. Patients and families often defer their medical care and pass on picking up medications or put off clinic visits, procedures or hospitalizations in order to pay rent/mortgages or buy groceries.

Unsurprisingly patients with CF and parents/caregivers of people with CF are at higher risk for anxiety and depression than those in the general population. Research shows that individuals with CF experience anxiety and depression at a rate that is 2-3 times higher than those in the general population. This is also true for their caregivers. CF creates daily demands and special challenges for people with CF and their families. Over time these ongoing stressors can take a toll on emotional health.

When patients and families had access to the CF Assistance Program through CSHN, it provided a sense of relief. Patient and families could use the fund to cover costs that no other programs exist to cover. Office visit and hospitalization copays, medical procedures, and necessary medical equipment were eligible for reimbursement. Medications not covered under any other manufacturer programs or co pay assistance were eligible to be reimbursed. Families and patients who did not qualify for other assistance and who have costly private insurance and copays, could access the CSHN CF Assistance Program to offset the financial burden of CF.

Time for patients with CF and their families is invaluable. Being able to ease the financial stress that is ever present in the world of CF means that patients and families can regain time in their day. Time means not having to stress about the cost of medical treatment or negotiating what one can and can't choose for medications. Time means that they can have quality time that is not consumed by CF. For

parents of newborns with CF, it means that they can focus on their baby and being first time parents. For adult patients, time is often borrowed. Average life expectancy for a person with CF is 46 years old. 46. Time not spent making phone calls to insurance companies or navigating how they will pay for daily living costs vs medical costs means that they have time to spend with friends and family.

Reinstating the CSHN CF Assistance program would say to people with CF in Maine- we see you, we hear you, and we care about the challenges you go through every day of your lives. It would honor the contributions that these individuals and families have made while persevering as public servants, care takers, and valued members of their communities. This is all while navigating the daily challenges of managing CF.

Thank you for your time today. I hope that you are moved by the testimonies that you hear today and are compelled to support these patients and families with restoring this incredibly important program.