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Senator Ned Claxton, Chair
Representative Michele Meyer, Chair
Members, Joint Standing Committee on Health and Human Services
100 State House Station
Augusta, ME 04333-0100

Re: LD 529 - An Act To Restore the Maine Center for Disease Control and Prevention Cystic Fibrosis Assistance Program

Dear Senator Claxton, Representative Meyer, and Members of the Health and Human Services Committee:

This letter is to provide information about LD 529, *An Act To Restore the Maine Center for Disease Control and Prevention Cystic Fibrosis Assistance Program*, and the potential impact of the proposed legislation, if enacted.

LD 529 proposes to establish the Cystic Fibrosis Assistance Program within the Maine CDC to provide reimbursement up to \$3,000 annually to adults and children diagnosed with cystic fibrosis (CF) for expenses related to care and treatment of CF. This bill requires the agency to adopt rules to implement this program which would be available to children and adults of all ages with CF. We offer the following information for consideration.

The Maine CDC, Maternal and Child Health Program (MCHP) is responsible for implementing 10-144 CMR chapter 272, Coordinated Care Services for Children with Special Health Needs, as authorized by 22 MRS, chapter 409, § 2001, to administer the Children with Special Health Needs Program (CSHN) to develop, extend and improve services for children who are disabled or who are suffering from conditions that lead to a disability. Chapter 272 has been in effect since 1988 and outlines eligibility requirements, including physician referral and diagnostic, age and income criteria to access allowances under CSHN.

CSHN is designed to provide assistance with obtaining resources and services related to medical care and to maximize the utilization of community resources so that care can be provided, to the extent possible, within a child's own community. CSHN is designed to assist children who are not currently eligible for MaineCare and/or Katie Beckett. 22 MRS § 2000 defines *child* as any person who has not attained the age of 22 years. The CSHN Assistance Program is funded solely through special revenue which is generated from the fees collected for filter paper required for newborn bloodspot screening. This program budget also funds four full-time staff, costs for the testing of genetic conditions, contracts for two genetic clinics for cystic fibrosis and metabolic disorders, and general program operating costs.

The CSHN Care Coordinator helps families navigate available services and regularly refers them to the following programs in Maine that assist individuals suffering from this serious medical condition, including CF, for which they may be eligible:

- Healthwell Foundation <https://www.healthwellfoundation.org/>
- CF Foundation Compass Program: <https://www.cff.org/Assistance-Services/Compass-Can-Help/What-Is-Compass/>
- The Assistance Fund <https://tafcares.org/>
- Robbie Foundation <https://robbiefoundation.com/>

Families have benefited from the resources above. Typically, there are eligibility requirements families must meet to receive help with out-of-pocket co-pays for prescriptions, medical appointment co-pays, insurance deductibles and premiums, financial and legal issues for CF families, incidental costs for medical treatment, adaptive equipment, assistive technology, and therapy not covered by insurance.

Under CSHN, a pilot program was developed in 2013 using surplus funding available at that time. This pilot targeted the needs of those participants with a diagnosis of CF and was available to adults of any age, income level and insurability, in addition to the children and young adults under the age of 22 who are the target population for CSHN. The pilot's expansion of assistance to adults older than 21 years of age was beyond the statutory authority of 22 MRS, chapter 272.. Participants were referred to this pilot program by two CF clinics in Maine, Northern Light-EMMC and Maine Medical Center. This pilot program reimbursed participants for travel expenses (i.e. mileage and hotel costs), medication copays, provider/hospital copays, durable medical equipment (DME) and medical supplies related to CF treatment and care. The Department established a \$3,000 maximum benefit per participant per year based on cost assessment of average annual healthcare costs for treating metabolic disorders. Looking back to data tracked for FY 16-19, the program served an average of 169 participants annually and expended nearly \$379,000 in total reimbursements for these years under the pilot program. The CSHN pilot program ended after 6 years due to lack of supplemental funding and the need to ensure appropriated funds were used for their intended purpose - to assist participants up to the age of 22 with special health needs – to be consistent with the governing authority.

If LD 529 is enacted, funding would need to be secured to cover costs of serving children and adult participants on an annual basis, estimated to be more than \$500,000 per year, and a program would need to be developed to manage the statutory obligations for an expanded group, including monitoring for compliance. As CSHN experienced during the CF pilot, standing up this program may lead to other adults with special health needs requesting similar support.

It may also benefit the Committee to know that in accordance with the MaineCare Benefits Manual (MBM), MaineCare members with CF can receive the medically necessary services for which they are determined eligible including (but not limited to): Physician—including specialists (pulmonary, gastrointestinal, surgeons, e.g.); APRN; Respiratory Therapists; PT/OT; Infusion therapy; Home Health; Dietary; Hospital; Pharmacy; Labs (including the sweat testing); Behavioral Health; and DME. The MaineCare drug formulary covers all the necessary medications, including the nutritional supplements and vitamins, though some of the more CF-

specific formulations such as the CFTR potentiators and antibiotics may need a Prior Authorization before the prescription is filled. DME covers the vest, the high frequency oscillators, nebulizers, oxygen, nasopharyngeal and gastrostomy tubes, etc.

There are 3 specialized CF Care Centers in Maine—2 in Portland (one for children, the other for adults) and 1 in Bangor; if the providers at these locations are enrolled in MaineCare, a member with CF may receive care at those facilities. If for some reason, the specific medically necessary services are not available at a location in Maine, MaineCare will approve services to be obtained out of state, and the State will pay for transportation to/from that facility. Furthermore, MaineCare members can obtain transportation to/from medical appointments for services covered by MaineCare using their non-emergency transportation benefit; under this benefit, a member or caregiver can receive mileage reimbursement if he/she provides the transportation to the appointment.

MaineCare does not cover massage therapies, health club memberships, experimental procedures or drugs, acupuncture, cosmetic surgery or housing. There may be circumstances when a member can obtain employment support and other community services if determined eligible by the Office for Family Independence and criteria set forth in the MBM.

It is possible that MaineCare expansion has allowed for the coverage of individuals who previously sought support from the pilot program.

In summary, the Maine CDC remains committed to working with families to find resources, including alternative sources of financial assistance, for those with special health needs, including metabolic disorders.

We respectfully recommend that there is consideration given to the limited funds available statewide and, similar to other State assistance programs and community resources, income eligibility and age or term restrictions be included in the legislation to ensure the CF program, unlike the pilot, is sustainable long term.

Thank you for your consideration of this matter. The Maine CDC is available to provide additional details for the Committee's consideration. We will continue to maximize our public health initiatives to optimize health for the people of Maine.

Respectfully,



Nancy Beardsley, Deputy Director
Maine Center for Disease Control and Prevention