

OFFICE OF POLICY AND LEGAL ANALYSIS

Date: March 23, 2021
To: Joint Standing Committee on Health & Human Services
From: Erin Dooling, Esq., Legislative Analyst

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

SUMMARY: This bill establishes the Cystic Fibrosis Assistance Program in the Maine Center for Disease Control and Prevention within the Department of Health and Human Services. It allows an adult or child diagnosed with cystic fibrosis to be reimbursed for expenses associated with the treatment and care of that condition up to \$3,000 annually.

PROPOSED AMENDMENT FROM TESTIMONY:

- *Maine Developmental Disabilities Council:* Consider changing this bill to include a report back to the committee next session that identifies common low-incident Children and Youth with Special Healthcare Needs disabilities, describes these children and youth's unmet needs and provides recommendations to improve the CYSHN Program so those children's needs can be met.

ADDITIONAL INFORMATION REQUESTED BY COMMITTEE:

- *Submitted to DHHS:* (See memo provided by DHHS)
 - Please provide an outline of the prior program that was in place and how it worked.
 - How much does the state receive from the maternal-child federal block grant, how much of it is encumbered and how is it being spent?
 - Does the Department have a list of other pediatric diseases that currently or in the past have received financial assistance?

- Can EPSDT funds for minor children be used for DME and other needs of cystic fibrosis patients?
- *Submitted to Maine Revenue Services: (Information not available)*
 - Please provide an estimate of what a nurse and a teacher would be contributing in taxes to Maine's economy over the course of 30 years.

FISCAL IMPACT: Preliminary fiscal impact statement shows \$501,000 of GF each year.