

Janet T. Mills  
Governor

Jeanne M. Lambrew, Ph.D.  
Commissioner



Maine Department of Health and Human Services  
Commissioner's Office  
11 State House Station  
109 Capitol Street  
Augusta, Maine 04333-0011  
Tel: (207) 287-3707; Fax: (207) 287-3005  
TTY: Dial 711 (Maine Relay)

## MEMORANDUM

**TO:** Joint Standing Committee on Health and Human Services  
**FROM:** Maine Center for Disease Control and Prevention  
**DATE:** March 22, 2021  
**RE:** Responding to questions re: LD 529

---

### **Please provide an outline of the prior program that was in place and how it worked.**

Under the Maine CSHN program, 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 cystic fibrosis (CF) specifically, and was presented as a short-term, or "pilot" initiative given the source of funds was limited. 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 of all ages 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. This pilot program operated for six years until it was terminated in 2019 following a thorough regulatory and budgetary evaluation. Of particular concern was the fact that, under the pilot program, funding was used for costs for adults older than 22 years of age with CF-when the CSHN program, by statute, was established for children and adults up to age 22.

### **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?**

The State receives approximately \$3,316,776 in formula-based funding each year in Title V Maternal and Child Health Services Block Grant (MCH BG), of which \$2,691,222 (82%) is spent on personnel and related indirect costs for approximately 22 positions and \$625,554 (18%) is encumbered on critical maternal child health services. These services include birth defects, genetics, cleft lip and palate, newborn bloodspot screening, partners in care, newborn hearing, and perinatal health. The grant is fully obligated and expended each grant period.

### **Does the Department have a list of other pediatric diseases that currently or in the past have received financial assistance?**

Currently, under CSHN Assistance Program, the diseases that receive assistance are metabolic diseases that mainly consists of Cystic Fibrosis and Phenylketonuria (PKU). This assistance program is funded through a special revenue account within the Maine Bloodspot Screening Program. The MCH BG funds assistance for children with a cleft lip and/or palate. These funds are used to provide bottles for the child's first year of life as well as help to pay for surgeries, lodging and other medically related items.

## **Can EPSDT funds for minor children be used for DME and other needs of cystic fibrosis patients?**

In general, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit would cover screening and treatment that is required to correct or ameliorate the effects of the condition. EPSDT can provide reimbursement for things that a child may need that is beyond what MaineCare has in our benefits package but is coverable by Medicaid in general. There is some nuance here in that an EPSDT request has to be:

- Prior Authorized,
- Shown to be scientifically valid,
- Not experimental, and
- Cost effective.

In short, if the DME item or CF treatment isn't otherwise covered in our benefits manual, it could be covered as long as it meets the conditions above. EPSDT may be used to cover treatments if the needed frequency exceeds current policy limits, if the duration exceeds current policy limits, and if the treatment is not of a type described in policy.