



**CYSTIC FIBROSIS IS A LIFE-THREATENING, GENETIC DISEASE THAT AFFECTS MORE THAN 30,000 CHILDREN AND ADULTS IN THE UNITED STATES.** Real progress has been made in improving the length and quality of life for people with CF, but there is still no cure, and we need your help. Together, we can build hope and add tomorrows.

## WHAT IT MEANS TO HAVE CYSTIC FIBROSIS

- CF is caused by a defective gene that makes the body produce unusually thick, sticky mucus that clogs the lungs, pancreas, and other parts of the body.
- This mucus makes it extremely difficult for people with CF to breathe and leads to life-threatening infections.
- To date, 14 CF therapies have been approved. Four of these treatments target the underlying cause of the disease including Trikafta™, which was approved by the FDA in 2019.
- Through the CF Foundation's efforts and support of research, drug development, and specialized care, the life expectancy of a child with CF has doubled in the last 30 years.

## CYSTIC FIBROSIS FACTS IN MAINE



~260 people with CF



3 accredited CF care center programs



6,000 CF advocates



2.4M in CF Foundation-awarded grants and research in the last five years



45% of children with CF rely on Medicaid and 42% of adults with CF rely on Medicaid

## CF FOUNDATION POLICY PRIORITIES

- Supplement existing funding for the Maine Children with Special Health Needs Assistance Program to restore previous services and eligibility for both pediatric and adult patients.

Sen. Anne Carney  
SD 29

Sponsor's Testimony in Support of LD 529 An Act To Restore the Maine Center For Disease Control and Prevention Cystic Fibrosis Prevention Assistance Program

Good morning Senator Claxton, Representative Meyer and esteemed members of the Health and Human Services Committee. I am Anne Carney, representing Senate District 29, South Portland, Cape Elizabeth and part of Scarborough.

I am pleased to introduce LD 529, An Act To Restore the Maine Center For Disease Control and Prevention Cystic Fibrosis Prevention Assistance Program. Cystic fibrosis is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time. In the lungs, the mucus clogs the airways and traps germs, like bacteria, leading to infections, inflammation, respiratory failure, and other complications. In the pancreas, the buildup of mucus prevents the release of digestive enzymes that help the body absorb food and key nutrients, resulting in malnutrition and poor growth. In the liver, the thick mucus can block the bile duct, causing liver disease. Men with CF can experience difficulty having children. An information sheet is attached to this testimony, and you can learn more about cystic fibrosis at the Cystic Fibrosis Foundation website.

Advances in medical care have greatly improved the quality of life and added decades to the lives of people with cystic fibrosis. Care includes medications for symptom relief and treatment of the genetic mutation, airway clearance techniques, pulmonary rehabilitation, and surgery. You will hear from Mainers with CF and their families, who can help you understand how LD 529 will support their medical care. I am so grateful that a constituent of mine, Patty Morris, brought this issue to my attention. Patty's adult daughter, Ali, has CF and finding ways to afford to cover the costs associated with CF has been challenging, even with her private health insurance, needs-based disease-specific grants, and drug manufacturer copay assistance.

The Cystic Fibrosis Prevention Assistance Program created by LD 529 reestablishes a pilot program that provided up to \$3,000 per year to help Mainers with CF and their families afford necessary care that is not covered by insurance. Effective CF-management can be extremely costly even for those with insurance coverage.

A study of the barriers to affording care and underuse of medication among those with CF showed that one in four people with CF had unmet prescription drug need in 2019, and that the likelihood of having unmet need was much higher among adults. Those insured through Medicare were particularly likely to have unmet prescription drug need, due to the cost-sharing aspects of Medicare and because they may be sicker.

Passage of LD 529 will ensure that Mainers with CF and their families can afford the care they need to manage this chronic disease and help those with cystic fibrosis to live longer and more fulfilling lives.