



March 31, 2023

North Carolina General Assembly
Legislative Building
16 West Jones Street
Raleigh, NC 2760

Dear Representative Cunningham,

On behalf of those living with cystic fibrosis (CF) in North Carolina, we thank you for supporting HB 76 and expanding Medicaid eligibility to childless adults with incomes up to 138 percent of the federal poverty level (FPL). In doing so, you have strengthened a vital safety net for the state's most vulnerable citizens, including those with CF.

About Cystic Fibrosis

Cystic fibrosis is a rare genetic disease that affects nearly 40,000 children and adults in the United States, including over 1,000 in North Carolina. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications.

While significant advances in care are helping people with cystic fibrosis live longer, healthier lives, the cost of care presents a barrier to access for many people with the disease. Many people with CF depend on multiple forms of insurance, and nearly three-quarters rely on some form of financial assistance. Still, according to a survey conducted by the George Washington University of more than 1,800 people living with CF and their families, nearly half of respondents reported delaying or forgoing care due to cost concerns. This can put patients at increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.¹

North Carolina Medicaid

Medicaid is a crucial source of coverage for people living with CF; roughly half of all children and one-fourth of all adults with CF in the state rely on the program for some or all of their health care coverage. Medicaid plays an important role in helping patients afford the specialized care they need to stay healthy—for many people with cystic fibrosis, it fills coverage gaps left by private insurance that would otherwise leave patients with unmanageable out-of-pocket costs. For people with CF, adequate coverage is not a luxury but a necessity—ensuring access to critical, life-sustaining care and treatments.

By expanding Medicaid eligibility to childless adults with incomes up to 138 percent of FPL, the state will extend coverage to an estimated 600,000 North Carolinians.² In doing so, the state will also draw down much-needed federal dollars and strengthen a vital safety net for North Carolina's most vulnerable residents, including those with cystic fibrosis.

¹ https://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1056&context=sphhs_policy_briefs

² <https://www.urban.org/research/publication/implications-medicaid-expansion-remaining-states-2018-update>

Thank you for supporting Medicaid expansion and improving access to care and coverage for North Carolinians, including those living with cystic fibrosis. As the health care landscape continues to evolve, we look forward to working with your office to improve the lives of all people with cystic fibrosis. Please consider us a resource moving forward.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with a large initial "M" and "D".

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation