



June 24, 2022

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

Dear North Carolina Representatives,

On behalf of those living with cystic fibrosis (CF) in North Carolina, we urge you to adequately fund Medicaid and expand program eligibility for childless adults with incomes up to 138 percent of the federal poverty level (FPL).

About Cystic Fibrosis

Cystic fibrosis is a rare genetic disease that affects more than 30,000 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, nearly half of respondents to a George Washington University survey of more than 1,800 people living with CF and their families reported delaying or forgoing care due to cost concerns, which 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 would extend coverage to an estimated 60,000 North Carolinians.² In doing so, the state could 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 your attention to this issue and for keeping the needs of people with CF in mind when forming the 2022-2023 budget. If you have any questions about CF or would like to discuss this issue further, please contact Sage Rosenthal, State Policy Specialist, at srosenthal@cff.org at (301) 841-2632.

Thank you for your attention to this important issue.

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