



Governor Ron DeSantis
State of Florida
The Capitol
400 S. Monroe St.
Tallahassee, FL 32399-0001

May 3, 2019

Dear Governor DeSantis,

On behalf of people with cystic fibrosis (CF) living in Florida, the Cystic Fibrosis Foundation writes concerning proposed changes to Medicaid retroactive eligibility and the potential impact on our community. HB 5201 would restrict the Medicaid retroactive eligibility period for nonpregnant adults to the calendar month in which a beneficiary applies for coverage. Previously, Medicaid covered health care costs up to ninety days before a patient's application date, providing an important safeguard for people with CF as they experience transitions in their health insurance.

Medicaid is a vital source of coverage for people living with cystic fibrosis.

Cystic fibrosis is a life-threatening genetic disease that affects approximately 1,600 Floridians and 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. As a complex, multi-system condition, people living with CF require targeted, specialized treatment and medications to maintain their health and well-being. This often requires intensive daily treatments, as well as regular visits to an accredited CF care center. 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. For this reason, it is vitally important that all people with CF have adequate, affordable health insurance, including the 280 adults living with cystic fibrosis in Florida who depend on Medicaid.

Medicaid retroactive eligibility is a critical component of Medicaid and should be protected.

HB 5201 would extend the elimination of Medicaid retroactive eligibility for nonpregnant adults 21 years and older. Previously, Florida beneficiaries received Medicaid benefits up to three months before their date of application. Effective February 1, 2019, Florida Medicaid limits coverage to only the month of application, beginning the first of the month. This waiver authority is set to expire on June 30, 2019 but HB 5201 would extend this policy.

Retroactive eligibility helps ensure continuous coverage for people with CF who experience changes in insurance status and become Medicaid eligible. There are many reasons why residents of Florida, including people with CF, may not be able to submit a timely Medicaid application when they become eligible. Someone with CF may be consumed by a complicated medical situation—such as an extended hospitalization—that may make it difficult to complete Medicaid paperwork. People may also not realize their coverage has lapsed until they seek care. For all of these reasons, it is important that Florida maintain retroactive eligibility to avoid any gap in coverage.



Without retroactive eligibility, people with CF may face significant out-of-pocket costs as a result. Cystic fibrosis care and treatments are costly and even with coverage. For instance, according to a survey conducted by George Washington University of 2,500 people living with CF, 45 percent of this patient population spend \$5,000 or more annually in out-of-pocket costs for copayments, coinsurance, and noncovered services. We urge to you reject this bill and any legislation that limits Medicaid retroactive eligibility so people with CF will not face gaps in coverage and costly medical bills.

The state should evaluate the effects of limiting Medicaid retroactive eligibility before making this change permanent.

As part of its demonstration waiver, the state plans to conduct an evaluation of the new limited Medicaid retroactive eligibility period. However, this policy has been in place for less than three months and we do not yet know the impact of this policy on Floridians' coverage. While we support encouraging consumers in Florida to proactively enroll in Medicaid, we urge you to veto HB 5201 and pause efforts to limit the retroactive eligibility period until the state can complete its assessment of the policy.

Please vote "no" on HB 5201.

By opposing HB 5201 and other policies that restrict Medicaid retroactive eligibility, you will preserve a safeguard against gaps in coverage and high health care costs for people living with CF and other serious illnesses. The Cystic Fibrosis Foundation appreciates your attention to this important issue. As the health care landscape continues to evolve, we look forward to working with the state of Florida 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 Dwight".

Mary Dwight
Senior Vice President, Policy & Advocacy
Cystic Fibrosis Foundation

A handwritten signature in black ink, appearing to read "Lisa Feng".

Lisa Feng, DrPH
Senior Director, Policy & Advocacy
Cystic Fibrosis Foundation

CC: Mary C. Mayhew, Secretary of the Agency for Health Care Administration
2727 Mahan Drive
Tallahassee, FL 32308