



October 1, 2020

Theresa Eagleson  
Director  
Illinois Department of Healthcare and Family Services  
201 South Grand Avenue East  
Springfield, IL 62763-0001

Dear Ms. Eagleson:

On behalf of the approximately 1,050 people in Illinois living with cystic fibrosis (CF), we write to urge the Department of Healthcare and Family Services (HFS) to preserve funding for Illinois Medicaid in the FY 2021 and 2022 budgets. Medicaid is critical to ensuring Illinoisans, including people with CF, have access to the high-quality, specialized care and treatments required to manage their health care. While we understand that these are unprecedented times, adequate funding for Medicaid is more important than ever for people living with CF and the providers who treat them.

#### **About Cystic Fibrosis & the CF Foundation**

Cystic fibrosis is a life-threatening genetic disease that affects 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. Cystic fibrosis requires targeted, specialized treatment and medications and most people with CF receive care at an accredited CF care center that provides multidisciplinary care in accordance with systematically reviewed, data-driven clinical practice guidelines. While great strides have been made in the treatment of the disease, CF continues to be a severe condition for which COVID-19 can pose serious health risks.<sup>1</sup>

As the world's leader in the search for a cure for CF and an organization dedicated to ensuring access to high-quality, specialized CF care, the Cystic Fibrosis Foundation accredits the more than 130 care centers in the United States—including 14 programs in Illinois—and supports the development of CF clinical practice guidelines. The CF Foundation also advocates alongside people with CF to ensure that they have adequate, affordable health coverage, including through programs like Medicaid.

#### **Illinois Medicaid**

Medicaid is a crucial source of coverage for patients with CF and we urge you to omit any reductions that may impact members' eligibility or benefits in future budget adjustment proposals. Almost half of children and 22 percent of adults with CF in Illinois depend on the program for some or all of their health care coverage. Medicaid plays an important role in helping patients afford the specialized care and treatments 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 unsustainable out-of-pocket costs.

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<sup>1</sup> Centers for Disease Control and Prevention. (2020, August 6). *Information for Healthcare Professionals: COVID-19 and Underlying Conditions*. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/underlying-conditions.html>

Care and treatment for CF is expensive, even for those with comprehensive coverage; reducing funding for Medicaid could disrupt access to care for vulnerable Illinoisans at a time when they can least afford it. According to a survey of 2,500 people living with CF conducted by George Washington University, one out of four people with CF and their families paid more than \$10,000 in out-of-pocket expenses over the course of 2018, not including premiums and deductibles. The same study found that more than two-thirds of people with CF delayed or skipped treatment in the preceding year due to cost and more than three-fourths relied on some form of financial assistance to help pay for their care. Medicaid helps to ease the cost burden of care for the 327 people in Illinois with CF who rely on the program for some or all of their health care coverage.

Additionally, we are concerned that cuts to Medicaid will further stress hospitals and providers already in a weakened financial state. In particular, reductions in provider reimbursement could have a lasting effect on CF care centers, which provide expert, coordinated care and specialized disease management. CF care centers are often housed within academic medical centers, which serve a disproportionate number of low-income patients. These medical centers rely on Medicaid reimbursement for a large portion of their revenue and are already in financially precarious positions due to reduced volume in elective procedures. Some care centers have been forced to furlough or lay off staff; additional cuts to provider reimbursement could further exacerbate these issues and result in centers losing critical staff.

#### **Policy Recommendation**

We understand that Illinois is facing budget constraints as it continues to mitigate the economic and public health effects of the COVID-19 pandemic. However, we urge you to protect people with CF and preserve Illinois Medicaid funding in any potential adjustments to HFS's FY 2021 and 2022 budgets.

We stand ready to serve as a resource as you address the current public health emergency (PHE) and greatly appreciate any steps you can take to ensure that people with CF are protected from inadvertent coverage losses once the PHE is lifted. We would be happy to connect you with local CF experts as HFS navigates Medicaid eligibility redeterminations and other financial issues related to the pandemic.

If you have any questions about CF or would like to discuss this request further, please contact **Lauren Ryan, Senior State Policy Specialist**, at [lryan@cff.org](mailto:lryan@cff.org) or (301) 841-2632.

Thank you for your attention to this important issue.

Sincerely,



**Mary B. Dwight**  
Senior VP of Policy & Advocacy  
Cystic Fibrosis Foundation