



July 19, 2022

Cecile Erwin Young  
Executive Commissioner  
Texas Health and Human Services Commission  
4900 N. Lamar Blvd.  
Austin, TX 78751-2316

Dear Executive Commissioner Young,

On behalf of the more than 2,100 Texans living with cystic fibrosis (CF), we write to urge the Texas Health and Human Services Commission (HHSC) to request full funding for Medicaid and the Children with Special Health Care Needs Program (CSHCN) in the FY 2024-2025 legislative appropriations request (LAR). Particularly given Comptroller Hegar's recent announcement that the 88<sup>th</sup> Texas Legislature will have record high revenue to spend, funding for crucial Medicaid and CSHCN services for Texans with CF to stay healthy should be a priority.

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

Cystic fibrosis is a life-threatening genetic disease that affects approximately 35,000 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, CF requires targeted, specialized treatment and medications. For those with CF, health care coverage is a necessity, and interruptions in coverage can lead to lapses in care, irreversible lung damage, and costly hospitalizations—compromising the health and well-being of those with the disease.

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 more than 130 care centers nationally, including 18 in Texas, that provide multidisciplinary, specialized care in accordance with clinical practice guidelines. As experts in CF care, the CF Foundation and our care centers understand the need for access to adequate, affordable health coverage, including through programs like Medicaid and CSHCN.

#### **Children with Special Health Care Needs**

As you begin negotiations for the 2024-2025 budget, we urge you to request full funding for the Children with Special Health Care Needs Program, which helps people with CF afford their care. For CSHCN enrollees with CF, the program is a crucial source of coverage – often filling gaps left by other plans or covering those without another source of insurance. By ensuring access to life-saving services, CSHCN helps people with CF maintain their health and well-being.

People with CF face a high-cost burden due to the intensive nature of their care and without adequate coverage, they are more likely to go without needed treatments. According to a recent survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care in 2019— including skipping medication doses, taking less medicine than

prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns.<sup>1</sup> Because CF is a progressive disease, patients who delay or forgo treatment face an increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations. CSHCN serves a critical role in ensuring people with CF can afford the care and treatments they need.

### **Medicaid**

Medicaid is also a crucial source of coverage for patients with serious and chronic health care needs, including CF, and we urge you to reject any proposed reductions to eligibility or benefits. Nearly half of children and approximately one in six adults living with CF in Texas depend on the program for some or all of their health care needs. For many with CF, Medicaid fills coverage gaps in private insurance that leave patients with unsustainable out-of-pocket costs. We hope that Texas is able to maintain Medicaid benefits and eligibility for those who rely on the program.

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The CF Foundation urges the HHSC to request full funding for Medicaid and CSHCN in the FY 2024-2025 budget to ensure that Texans living with CF have access to the critical health care they need.

We appreciate the opportunity to comment on the upcoming legislative appropriations request ahead of your formal review. If you have any questions about cystic fibrosis or would like to discuss the importance of CSHCN to the CF community, please contact Sage Rosenthal at [srosenthal@cff.org](mailto:srosenthal@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

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<sup>1</sup> Seyoum, Semret; Regenstein, Marsha; and Nolan, Lea, "Cost, coverage, and the underuse of medications among people with CF" (2020). Health Policy and Management Issue Briefs. Paper 57.  
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