CYSTIC FIBROSIS
FOUNDATION®

November 19, 2021

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).

**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, patient-centered, specialized care in accordance with systematically reviewed, data-driven 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 CSHCN.

**Children with Special Health Care Needs**
As you begin negotiations for the 2024-2025 budget, we urge you to allocate full funding for the Children with Special Health Care Needs Program, a state-run program that helps people with CF afford the high cost of their care. For eligible patients, including those with CF, CSHCN is a crucial source of coverage – often filling important gaps in coverage left by other plans or covering those without another source of insurance. For people with CF, CSHCN helps cover the cost of care, ensuring access to life-saving services and allowing people with CF to maintain their health and well-being.

The high cost of care continues to impact access to care for people with CF and can lead to adverse health outcomes. 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.[1] Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

**Medicaid Funding**

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 four adults living with CF in Texas depend on the program for some or all of their health care needs. Medicaid plays an important role in helping people with cystic fibrosis afford the specialized care and treatments they need to stay healthy. For many with CF, Medicaid fills coverage gaps in private insurance that leave patients with unsustainable out-of-pocket costs

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The CF Foundation urges the HHSC to request full funding for Medicaid and the Children with Special Health Care Needs Program (CSHCN) in the FY 2024-2025 budget to ensure that Texans living with CF have access to the critical health care they need to maintain their health and avoid unnecessary hospitalizations.

We appreciate the opportunity to comment on the upcoming legislative appropriations request. 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 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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[1] 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. https://hsrc.himmelfarb.gwu.edu/sphhs_policy_briefs/57