



September 14, 2022

Haley Turner
Deputy Executive Commissioner of Community Services
Texas Health and Human Services Commission
4900 N. Lamar Blvd.
Austin, TX 78751-2316

Cc: Keisha Rowe, Associate Commissioner, Rehabilitative and Independent Services
Lindsay Rodgers, Associate Commissioner, Health and Developmental Services
Ellen Watkins, Director, Office of Primary and Specialty Health

Dear Deputy Executive Commissioner Turner,

On behalf of the more than 2,100 Texans living with cystic fibrosis (CF), we write to thank you and your team for the recent waitlist pulls of patients who gained access to the Children with Special Health Care Needs Program (CSHCN). As a result of your ongoing work to improve the program for enrollees, there are very few people with CF currently on the waitlist.

About Cystic Fibrosis & the CF Foundation

Cystic fibrosis is a life-threatening genetic disease that affects close to 40,000 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 know, the Children with Special Health Care Needs Program 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. CSHCN helps people with CF maintain their health and well-being by ensuring access to life-saving services. For example, at the Texas Tech University Health Sciences Cystic Fibrosis Center, two recent enrollees of the program who were previously struggling with weight gain, decreased lung function testing, and malabsorption symptoms are now able to maintain their treatment and gain weight as a result of the benefits of the CSHCN program.

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— 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 an increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations. CSHCN serves a vital role in ensuring people with CF can afford the care and treatments they need.

The CF Foundation thanks the Texas Health and Human Services Commission and the leaders of CSHCN for continuing to ensure that Texans living with CF have access to the critical health care they need. If you have any questions about cystic fibrosis or need any additional information on the value of the program for our 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

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