



November 21, 2019

Dr. Courtney N. Phillips  
Executive Commissioner  
Texas Health and Human Services Commission  
4900 N. Lamar Blvd.  
Austin, TX 78751-2316

Dr. Phillips:

Thank you for the opportunity to share input on the department's upcoming legislative appropriations request. On behalf of the more than 2,000 Texans living with cystic fibrosis (CF), we write to urge the Texas Department of Health and Human Services to request appropriations to help relieve the waitlist for the Children with Special Health Care Needs Program (CSHCN). While the program serves an important role for many with CF, others who are eligible for the program remain on the waitlist without access to coverage. Relieving the waitlist will ensure eligible Texans have access to the critical health care they need to maintain their health.

#### **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. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. Most people with CF get care at an accredited CF care center that provides multidisciplinary, patient-centered, specialized care in accordance with systematically reviewed, data-driven clinical practice guidelines. 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—and supports the development of CF clinical practice guidelines. The CF Foundation also advocates to ensure people with CF have adequate, affordable health coverage, including through programs like CSHCN.

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

For eligible patients, including those with CF, Children with Special Health Care Needs (CSHCN) is a crucial source of coverage—often filling important gaps 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. CSHCN provides a safety net for Texans with CF who might otherwise be left without access to care.

People with CF are particularly vulnerable to decreases in funding for programs like CSHCN. 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 pay more than \$10,000 in out-of-pocket expenses each year, not including premiums and deductibles. In order to make ends meet, 78 percent of people received some form of financial assistance to help pay for their care in 2017. Programs like CSHCN help to ease the burden of the cost of care, especially for low-income Texans without access to insurance.

### **CSHCN Impact on People with CF**

Unfortunately, over recent years, the CSHCN program has seen a rise in enrollment and decline in funding. As a result, the waitlist for the program has continually increased and, as of earlier this year, included more than 75 people with CF. Decreased or delayed access to care resulting from programmatic funding reductions can be devastating for people with CF who rely CSHCN.

Specifically, we have seen firsthand how the extensive waitlist for the CSHCN program has reduced access to care for patients and increased financial burdens for both patients and hospitals. For instance, we know of one patient in his early 20s who is very ill with low lung function and no insurance. While he is eligible for CSHCN, he has been on the waitlist for more than a year and has instead been receiving care through his hospital's pediatric charity care program. Because the adult center does not have a similar program, this patient is unable to transition to the adult center, which would be better equipped to handle the specific needs of an adult with CF. At least 10 patients at the same CF center are in a similar position. Should the waitlist be relieved or eliminated, these patients and many more like them would be able to access appropriate care that meets their needs and hospitals would be no longer be burdened with the full cost of their care.

### **Policy Recommendation**

The CF Foundation urges the Texas Department of Health and Human Services to request appropriations to help relieve the waitlist and ensure vulnerable Texans, including both children and adults with CF, have access to the critical health care they need to maintain their health.

We appreciate the opportunity to provide input on these important appropriations requests and stand ready to answer any questions you may have about cystic fibrosis, CF treatments, or the need for access to CSHCN. Please consider us a resource moving forward and contact Lauren Ryan at [lryan@cff.org](mailto:lryan@cff.org) or (301) 841-2632 or more information.

Sincerely,



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