

March 16, 2023

Representative Sam Harless Chair, Select Committee on Health Reform Texas House of Representatives P.O. Box 2910 Austin, Texas 78768-2910

#### Dear Chairman Harless:

On behalf of people with cystic fibrosis (CF) living in Texas, we write to express our support for HB 1283, which would retain prescription drug coverage decisions at the state level, and urge you to schedule a hearing for HB 1283 in the House Insurance Committee as soon as possible. Currently, administration of the Medicaid and Children's Health Insurance Program (CHIP) formulary and preferred drug list is set to transition from the Vendor Drug Program to managed care plans on August 31, 2023. We are concerned that such a transition would result in disruptions to care for people with CF and increased administrative burden for care teams. By passing HB 1283, you will ensure that all Medicaid members have uninterrupted, consistent access to the therapies they need to stay healthy, regardless of their managed care plan.

#### **About cystic fibrosis**

Cystic fibrosis is a life-threatening genetic disease that affects nearly 40,000 children and adults in the United States, including over 2,220 in Texas. Roughly a third of children and adults living with CF in the state depend on Medicaid for some or all of their health care coverage. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. If left untreated, infections and exacerbations caused by CF can result in irreversible lung damage and premature death, usually by respiratory failure. As a complex, multi-system disease, CF requires an intensive treatment regimen including multiple medications. While these therapies are helping people with CF live longer, healthier lives, patients often encounter administrative barriers to accessing them.

# Please support HB 1283 to retain a single state Medicaid and CHIP formulary

Texas is currently set to transition from a single state Medicaid formulary and delegate prescription drug benefit authority to managed care plans. Medicaid provides a vital source of coverage for nearly a third of Texans with CF. HB 1283 mandates that the Vendor Drug Program administration of the Medicaid and CHIP formulary and preferred drug list is left intact at the Health and Human Services Commission. The current formulary serves people with CF well and retaining this system will ensure continued access for Texans with CF.

The Cystic Fibrosis Foundation has seen access barriers with some managed care plans that impose clinically inappropriate, restrictive criteria. People with CF have an intensive treatment regimen—including modulator therapies, inhaled antibiotics, mucociliary clearance treatment, and pancreatic enzyme replacement therapy, among others—and treatments for CF are not interchangeable. People with CF must take the same medications year after year, and often for life, to maintain their health and

clinically inappropriate criteria—such as unnecessary prior authorizations—can delay the start or continuation of needed treatments, leading to adverse health outcomes for patients. If the Medicaid and CHIP drug benefit is shifted from one state run formulary to 18 different managed care plans and six pharmacy benefit managers, it also creates a significant administrative burden for care teams as they navigate different policies and coverage requirements among each plan. Retaining coverage decisions at the state level will ensure continued balance between cost and patient safety while maintaining uninterrupted access to therapies and treatments for Texans living with CF.

The Cystic Fibrosis Foundation appreciates your attention to this important issue for the CF community in Texas.

Sincerely,

# Mary B. Dwight

Chief Policy & Advocacy Officer Senior Vice President, Policy & Advocacy Cystic Fibrosis Foundation

# Rodolfo Amaro, MD, FRCP(C), FAAP, FCCP

Director, CF Care Center University of Texas Health Center at Tyler

#### Danielle Beachler, MD

Director, Pediatric CF Care Center
Dell Children's Medical Center of Central Texas

### Adaobi Kanu, MD

Director, CF Care Center Texas Tech University Health Sciences Center

# Krishna Pancham, MD

Director, Pediatric CF Care Center Cook Children's Medical Center

# Jon Roberts, MD, FCCP

Director, Pediatric CF Care Center Driscoll Children's Hospital

#### Fadel Ruiz, MD

Director, Pediatric CF Care Center Texas Children's Hospital/ Baylor College of Medicine

### Donna Beth Willey-Courand, MD

Director, Pediatric CF Care Center University of Texas Health Sciences Center - San Antonio