HOUSE OF REPRESENTATIVES
COMPILATION OF PUBLIC COMMENTS

Submitted to the Committee on Health Care Reform, Select
For HB 1283
Compiled on: Thursday, April 6, 2023 8:52 AM

Hearing Date: April 6, 2023 7:30 AM

Teresa Jalomo, Community Liaison
APC Homemakers
Corpus Chrisit, TX

HB 1798 By Howard
Community Care Payment Advisory Committee and Strategic Plan
Community Care Payment Advisory Committee and Strategic Plan

Lori Carreon
Cystic Fibrosis Foundation
Houston, TX

On behalf of people with cystic fibrosis (CF) living in Texas, we urge you to support HB 1283, which would retain prescription drug coverage decisions at the state level. 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 this would cause 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.

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.

We have 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.

Karen Utley
Self
Clute, TX

I support repealing the sunset of the single formulary for Texas Medicaid. As a parent of a severely disabled child with a genetic epilepsy on a Medicaid waiver, I cannot imagine the nightmare medication management would become if every MCO has their own formulary. Please protect children like my daughter by making sure the great state of Texas keeps a single formulary for Texas Medicaid.

Cindy Fleharty
Self - caregiver to medically complex child
Leander, TX

Doctors should choose which medications are prescribed and the formulary should be consistent across MCOs.

Cristina Villarreal
Self, stay at home mom
Rio Grande City, TX

As a mom of a medically fragile child, I am registering in support of HB 1283. I believe it is critical to maintain a statewide drug formulary. Relinquishing this responsibility to the MCOs would create chaos for parents, such as myself, and put children's lives at risk. I know my child does not have the time to go through a list of medications that might help her. She also does not have the ability to verbalize how she feels. I believe a statewide formulary is best for my child and anyone who needs prescription medications to survive.

Pari Schroeder
Self
Conroe, TX

Many constituents rely on life saving medications. My medically fragile children require compounded and specific medications due to disease. Insurance often does not know how to spell my family’s diseases, have knowledge of or know how to properly treat. Not only is this dangerous for the patient and their family but also cost all tax paying citizens. Institutions owning Medicaid insurance plans and having a financial gain in the process is an injustice to patients requiring Medicaid and specific medications. Families will also have additional hurdles when faced with drugs that don’t match the formulary.

Brizeida Linares
Protect Texas fragile kids
Mesquite, TX

I support HB1283, which will eliminate the sunset provision and maintain the statewide prescription drug formulary in perpetuity. I have a son with developmental delays that takes a lot of prescriptions drugs and cannot take generic drugs. Thank you

Rebecca Galinsky
Protect TX Fragile Kods.
Arlington, TX

We support HB 1283 (Oliverson) as written.

Rebecca Galinsky, Parent & advocate
Protect TX Fragile Kids
Arlington, TX

I support HB 1283.

Batool Hassan
Self - Global Logistics Managwe
Sugar Land, TX

I support this bill. My son is medically fragile which is already a challenge but fighting insurance for meds he needs is even harder. I just spent 2 weeks trying to get something he has been on for months approved while begging CVS to help us and getting “loaners” to avoid him having a seizure due to missed meds. Very stressful! Please let the doctors decide what meds are needed, not insurance companies that are trying to save their pockets without caring for the patient.

Eric Kunish, Chair
National Alliance on Mental Illness-Central Texas Affiliate
Austin, TX

I support this bill!

Lynn Wilson, VP, Director of Patient Led Research
Myositis Support and Understanding
Taylor Lake Village, TX

Myositis Support and Understanding Association, a rare disease patient advocacy group, with an estimated 10,000 patients in Texas living with Myositis, many who depend on Medicaid to provide the life saving drugs they need, urges the passing of HB 1283. This bill is critical to maintain the Medicaid Single Formulary and Preferred Drug List: (1) maintaining oversight and transparency for the nearly $200M in drug rebates used to fund the Medicaid program, (2) safeguarding patient protection have public input at Drug Utilization Review Board in determining the drug list, and (3) proper stewardship of our tax dollars, which are already being used to purchase the lowest net cost drug first, regardless of whether it is a branded drug or a generic. We want Texas to remain a State of Access for all Texas rare disease patients and their families. We urge the legislature to support this very important bill.

Andrea Sieling
Self/Mother to a Medically Fragile Child
Frisco, TX

I am in support of this bill.

Andrea Sieling
Self/mother to a medically fragile child
Frisco, TX

My daughters medical team should be the ones who make the decisions on the best medication for my daughter, NOT an insurance company who knows nothing about my child’s needs.