HEALTH CARE BILL OF RIGHTS

for Individuals with

CYSTIC FIBROSIS

This Health Care Bill of Rights gives voice to the health care needs of the 30,000 Americans who suffer from cystic fibrosis, the most common fatal genetic disease in North America. Individuals with cystic fibrosis have complex medical needs.

These principles ensure that individuals with cystic fibrosis can access quality health care to achieve and maintain their best state of health. By codifying these rights, policymakers commit the federal and state health care systems to support the long-term health of individuals with cystic fibrosis.

INDIVIDUALS WITH CYSTIC FIBROSIS HAVE THE RIGHT TO ROBUST INSURANCE COVERAGE

Whether it's coverage via a state Medicaid program, an affordable independent policy, or as a member of their parents' or spouse's policy, individuals with cystic fibrosis must have the ability to obtain insurance coverage that will not use lifetime caps to limit their care.

Individuals with cystic fibrosis should not be denied coverage because they have a genetic pre-existing condition or cannot meet prohibitive work requirements. Further, they should not be discriminated against based on present or predicted disability, degree of medical dependency or any other potentially disqualifying trait, such as age.

INDIVIDUALS WITH CYSTIC FIBROSIS HAVE THE RIGHT TO ACCESSIBLE DOCTORS AND SPECIALISTS

Given the complicated and ongoing nature of cystic fibrosis, individuals with the disease need the ability to see their primary doctor; their condition also requires specialist care. Thus, robust, comprehensive networks of health care providers are vital for both public and private coverage systems. These ensure that individuals with cystic fibrosis can access timely and appropriate medical care without unreasonable co-pays.

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INDIVIDUALS WITH CYSTIC FIBROSIS HAVE THE RIGHT TO ACCESSIBLE MEDICATIONS

Individuals with cystic fibrosis struggle to breathe, and they face chronic and debilitating lung infections. For decades, medications have been able only to help relieve the symptoms, but recent breakthroughs have produced treatments that actually address the disease's cause. Individuals with cystic fibrosis have the best opportunity to maintain, and potentially improve, their health when they can readily access the medications and therapies prescribed by their physician.

Eliminating barriers like step therapy and cost sharing for brand-name or specialty tiered medications is integral to access. So is the ability to take an ongoing prescription without repetitive prior authorizations or prohibitive co-pays. Unnecessary delays that keep individuals from their medication can have long-term or permanent effects, because cystic fibrosis is a progressive disease. Unnecessarily interrupting treatment can also jeopardize the stability of an individual's health.

INDIVIDUALS WITH CYSTIC FIBROSIS HAVE THE RIGHT TO POLICIES THAT ENCOURAGE INNOVATION

Pharmaceutical companies have historically been hesitant to research or manufacture therapies given the financial risk associated with developing drugs for "orphan diseases." These are diseases that affect fewer than 200,000 people. However, for each of these people, cystic fibrosis can affect every area of their life. For this reason, individuals with cystic fibrosis depend on continual research and development to discover the innovative therapy that could change their lives forever.

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Cystic Fibrosis Engagement Network

The Cystic Fibrosis Engagement Network serves as a leading educational and advocacy organization focused on policy matters impacting cystic fibrosis patients' access to optimal care.

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