

## Cystic Fibrosis and Access to Care

Cystic fibrosis (CF) is a life-threatening genetic disease that affects 30,000 people in America. The CF community has seen a dramatic improvement in life expectancy for those with the disease in the past 50 years. Thanks to innovative and aggressive research, more therapies continue to emerge to treat the disease.

Continued progress depends on innovative research and ensuring those with the disease have access to the care and therapies recommended by CF experts without facing an unreasonable economic burden. For more and more people with cystic fibrosis, the cost of these life-lengthening therapies is becoming unaffordable and inaccessible.

*Emma is a teenager in Ohio who has cystic fibrosis. She has private insurance through her parents' employer.*

### **Rising Insurance Costs Affect Access**

While 97 percent of people with cystic fibrosis are insured, many face the daunting reality that despite their coverage they may not be able to afford the therapies that they need to keep themselves alive and healthy. As people with cystic fibrosis live longer, the number of patients who reach financial limits to their care is expected to rise.

A 2009 survey of people with cystic fibrosis found:

- Premiums and out-of-pocket costs have risen up to 20%
- 14% of people have reached an annual limit on their insurance coverage
- 3% of people have reached a lifetime limit on their insurance coverage

*Emma's insurer recently removed one of her \$40 co-pay medications from its formulary. Her family now must pay 50% of the cost of the drug, which amounts to \$800 a month, which the family cannot afford.*

### **Under-Insurance: Struggling to Access Care**

People with cystic fibrosis are living longer lives, yet an increasing number of people now face the issue of under-insurance, that is, health insurance coverage that is not adequate to afford life-sustaining and life-lengthening care. People with cystic fibrosis are forced to make difficult choices about their health care:

- 27% said they missed doses or took less than prescribed due to cost concerns
- 21% said they delay or skip medical care due to cost

*Emma waited over a month to get assistance with the \$800 co-pay. While she waited for help, Emma went without the needed medication and contracted an infection in her lungs.*

### **The Cost of Care**

Damage done to the body by cystic fibrosis is cumulative in nature and delay in seeking care can prove deadly. The cost of under-insurance or no insurance is the same: people who need care go without it or access care at an inadequate level. An analysis of the cost of CF treatment shows that CF care is expensive for patients.

- Commercially insured patients with CF have medical costs 9 to 13 times higher than the average commercial member.

Yet the cost of care represents only a fraction of the overall health care costs. Health insurance plans that place CF medications in high co-pay or coinsurance tiers as a way to save money are likely to see less than a 0.01% decrease in premiums. This cost-shifting is devastating for patients who as a result can no longer afford critical medications that have no cheaper generic alternatives.

*Because of the loss of her \$40 co-pay, Emma spent three weeks in the hospital at a cost of \$80,000. She also suffered permanent lung damage from which her physician says she will not recover.*

# **The Cystic Fibrosis Foundation Urges Congress to Improve Access to Care and Ensure Quality of Care**

The Cystic Fibrosis Foundation is the primary sponsor of critical research that is making tremendous advances toward a cure and control of this disease. In the past five years, the Foundation has invested more than \$660 million in medical programs dedicated to advancing life-sustaining treatments and a cure for cystic fibrosis.

The CF community has seen a dramatic improvement in life expectancy for those with the disease in the past 50 years. In order to continue this remarkable progress, those with the disease must have access to innovative treatments and care recommended by CF experts without unreasonable economic barriers.

Today, the CF Foundation urges Congress to join us in our effort to add more tomorrows to the lives of those with CF.

## **To ensure that people with cystic fibrosis receive access to the care and treatment they need to help them live longer and healthier lives:**

### **Reform the Health Insurance System**

- Elimination of pre-existing condition exclusions that can block access to health insurance and assurance of portability of coverage, to ensure coverage and prevent economically unproductive job lock
- Protection against out-of-pocket costs, including deductibles, co-payments, and co-insurance, that prevent access to care for chronic diseases
- Protection against catastrophic expenses, which may require assistance to employers whose insurance plans may cover individuals with such expenses. A program to cover catastrophic expenses should also address the issue of annual and lifetime spending caps
- Elimination of the Medicare waiting period for disabled Americans to protect against disruptions in care for those individuals

### **Reform the Delivery of Care**

- Establishment of a system for coordination of chronic care to enhance the quality of care and prevent gaps in care for those with chronic and life-threatening illnesses
- Development of an efficient method for coverage determinations that rapidly incorporates into the system of care those therapies that will extend and/or improve quality of life for those with CF
- Implementation of a quality assessment and monitoring system that will inform decisions that will boost the quality of care

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