

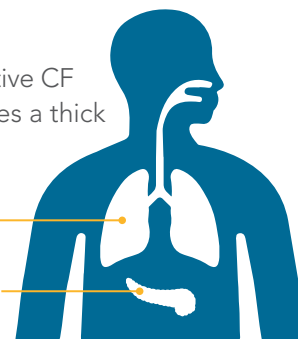
# My Coverage Matters:

## Cystic Fibrosis & Health Care Reform

### ABOUT CYSTIC FIBROSIS

CF is a complex, genetic disease that primarily impacts the lungs and digestive system. Daily treatment regimens can be extremely time-consuming, sometimes taking hours each day. Promising new therapies that address the underlying cause of the disease and a focus on continuous improvement in care have led to increases in the average life expectancy. In 1955, when the Foundation was established, children born with CF often died before reaching elementary school. Today, more than half of people with CF are age 18 or older, and many are living into their 30s, 40s and beyond.

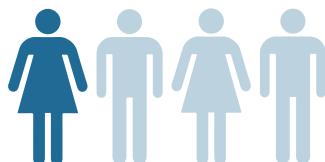
The defective CF gene causes a thick buildup of mucus in the **lungs** and the **pancreas**.



### COST AND CYSTIC FIBROSIS

CF care is complex and often requires intensive daily treatments, as well as regular visits to an accredited care center to maintain health and well-being.

While nearly all people with CF have insurance, about **1 in 4 people skip or delay care or alter doses of prescribed medications due to cost concerns** – twice as often as adults in the general population.<sup>1,2</sup> People with lower household incomes or high out-of-pocket costs are twice as likely to skip care.<sup>3</sup>



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#### Out-of-Pocket Cost Concerns

- 1. PREMIUMS:** Half of people with CF spend \$300 or more on monthly premiums to maintain coverage.
- 2. MEDICATION EXPENSES:** Half of people with the disease spend over \$200 each month on CF-related medications.
- 3. CLINIC VISIT EXPENSES:** Some patients can pay as much as \$550 per visit to visit their care team.
- 4. OUT-OF-NETWORK SERVICES:** When a service or treatment isn't covered by insurance, patients may be faced with an unexpected bill for needed care.
- 5. HOSPITALIZATION COSTS:** Because of complications, 37 percent of people with CF experienced one or more hospitalizations per year with an average of 22 days spent in inpatient care.<sup>4</sup> This can greatly impact a family's financial burden.

People with CF need specialized care from a multidisciplinary care team, specialty prescription drugs

and may undergo unexpected and costly hospitalizations. Health care costs can accumulate very quickly, making it easy to reach the ceilings defined under annual and lifetime coverage maximums. The result can be devastating for people with CF – leaving them stranded without any health care coverage and exposing them to the full cost of care.



A father of two daughters with CF reported that together his children hit over **\$1 million** a year in medical expenses.

### PRE-EXISTING CONDITIONS

Individuals with CF must be assured:

- 1** They will be able to purchase health insurance
- 2** Their health insurance will not exclude services related to CF
- 3** They will not be charged higher premiums because of their disease

All three of these policies are absolutely essential to ensuring that individuals with CF have access to affordable, adequate health insurance – no single policy is sufficient on its own. For instance, while it is critical that people with CF are able to purchase insurance, the prospect of facing a higher premium because of an unforeseen gap in coverage or having CF services carved out of a benefit package pose serious threats to the ability of individuals with CF to maintain their health.

Some of the proposals to change coverage and control costs could **jeopardize access to lifesaving treatments** that have added decades of life for people with cystic fibrosis.

1 CF Patient Financial Concerns Survey, Cystic Fibrosis Foundation, 2015.  
2 Peterson-Kaiser Health System Tracker, 2015.  
3 CF Patient Financial Concerns Survey, Cystic Fibrosis Foundation, 2015.  
4 CF Patient Registry, 2015.

HIGH RISK POOLS & CYSTIC FIBROSIS

Experience with high risk pools indicates that this type of coverage would be unaffordable and inadequate for many people with CF.

- High premiums, usually 150–200 percent of the average non-group rate, made coverage unaffordable for many.<sup>5</sup>
- Waiting periods of up to 12 months left patients struggling to access critical services while they were waiting for coverage.<sup>6</sup>
- Annual and lifetime limits left people with CF unable to access vital care after hitting their coverage maximum.

MEDICAID FINANCING & CYSTIC FIBROSIS

As a program that covers many people with complex health conditions, including CF, Medicaid must be responsive to changes in treatments and therapies for high need populations. However, because financing reforms such as block grants and per capita caps would be tied to historical costs, **these policies would not accommodate innovative, new therapies and technology.** This is particularly important for people living with CF, many of whom have seen dramatic improvements in their health and quality of life in recent years from new therapies that have come to market.

Moreover, if the cost of maintaining current eligibility and benefits outpaced annual increases in the block grant amount or per capita cap, states may choose to constrain eligibility, reduce benefits, lower provider payments or increase cost sharing. For people with CF covered by Medicaid, this could prevent them from accessing needed care and may result in declining health.

OVER HALF & A THIRD OF CHILDREN & ADULTS living with CF rely on Medicaid coverage for some or all of their health care needs.

KAREN

NAME: Karen (adult living with CF)  
FAMILY INCOME: \$63,600  
INSURANCE: Employer-sponsored  
OUT-OF-POCKET: • \$5,000 medical deductible  
• \$1,000 pharmacy deductible  
• Tiered copays + 20 percent coinsurance on specialty drugs  
ANNUAL EXPENSES: \$82,200 in copays + coinsurance\*  
\$6,000 in total deductibles  
\$1,200 annual premiums  
=\$89,400 each year

Karen receives assistance from private foundations to help with her out-of-pocket costs. Income and expense figures are estimates.  
\*This plan is not subject to limits on out-of-pocket

JOHN & JULIE

NAME: John and Julie (parents of two children with CF)  
FAMILY INCOME: \$34,000 a year  
INSURANCE: Employer-sponsored/Medicaid  
OUT-OF-POCKET: • \$2,000 up front each month, prior to insurance reimbursement  
• 20 percent coinsurance on all drugs  
• \$8,000 family annual out-of-pocket maximum for pharmacy costs  
ANNUAL EXPENSES: \$26,688 prescription coinsurance  
\$7,200 annual premium  
= \$33,888 each year

John and Julie have two children with CF and an annual income of \$34,000. The family is insured by John’s employer and the children are also covered by Medicaid. While the children have two types of coverage, the insurers refuse to coordinate benefits and the family must pay \$2,000 out-of-pocket each month and request reimbursement from their secondary insurer.

John and Julie also struggle to get their children to the nearest accredited care center, nearly 70 miles from their home. With one car for the family, John and Julie must decide between John going to work or taking his children to the clinic. And while the visit is covered, the family must manage the cost of gas for a 140-mile trip, parking and food for the day.

Income and expense figures are estimates.

ABOUT THE FOUNDATION

The Cystic Fibrosis Foundation promotes policies to help ensure that all people with cystic fibrosis have access to high-quality, specialized care and adequate, affordable health insurance. We also support policies that contribute to a sustainable health care system that best serves all people living with the disease.

Our core principles include:

- **ADEQUACY:** Adequate health insurance covers therapies and care delivered by an accredited care team using the latest research, clinical guidelines and best practices.
- **AFFORDABILITY:** Affordable health plans help ensure access to needed care in a timely manner from an experienced provider without undue financial burden.
- **AVAILABILITY:** Available health coverage provides adequate benefits at an affordable cost regardless of an individual's income, employment, health status or geographic location.

<sup>5</sup> Karen Pollitz, “High-Risk Pools for Uninsurable Individuals,” Kaiser Family Foundation, July 2016.  
<sup>6</sup> Ibid.