

INVESTMENT IN RESEARCH SAVES LIVES AND MONEY

Cystic Fibrosis

Cystic fibrosis is caused by a defective gene that makes the body produce mucus that clogs the lungs, pancreas, and other parts of the body. Clogged airways, chronic coughing, and lung infections can lead to permanent lung damage and cause premature death.¹

Groundbreaking partnerships between the Cystic Fibrosis Foundation, federally-funded academic researchers, and industry -- emblematic of the power of patient engagement and the importance of each segment of the R&D pipeline -- have driven remarkable progress against CF. Continued cross-sector commitment and investment can, and must, lead to a cure for this disease.

TODAY

More than
30,000 Americans and
70,000 individuals worldwide
live with CF.²

More than
50%
of those living with CF today
are over the age of 18.²

COST

\$1.2 billion:

Aggregate cost of hospital visits for CF each year.³

\$131,000:

In the United States, the annual cost of medical expenditures for individuals living with CF.⁴

Research Delivers Solutions

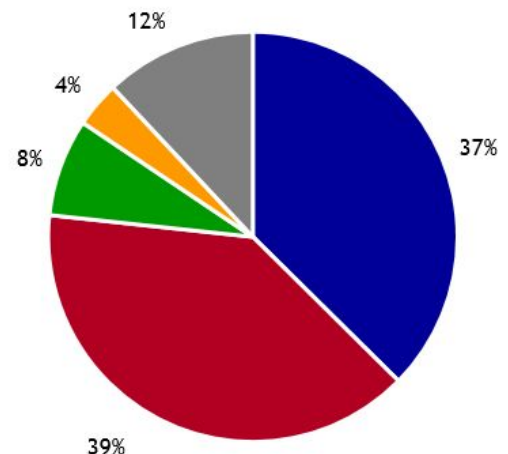
Advances in newborn screening techniques have significantly improved the ability to detect and diagnose CF at birth. In 2000, **only 8%** of those living with CF were diagnosed at birth. Today, that number has **increased to over 75%**.^{2,3}

Since the discovery of the CF gene **30 years ago**, research has led to the creation of **13 drugs**, including **3 that treat the underlying cause** of the disease.⁵

Infections remain a **leading cause** of lung dysfunction among individuals living with CF. With support from the **Cystic Fibrosis Foundation's Infection Research Initiative**, researchers are examining new ways to detect, diagnose, and treat infections as well as ways to optimize current treatments to improve effectiveness and reduce treatment burden.⁵

Majority Support Federal Incentives for Private Investment in New Treatments & Cures

How important is it for the federal government to incentivize greater private sector investment in new treatments and cures?



■ Very important ■ Somewhat important
■ Not too important ■ Not at all important
■ Not sure

Source: A Research!America poll of U.S. adults conducted in partnership with Zogby Analytics in January 2019

1. Baby's First Test, "Cystic Fibrosis", US Department of Health and Human Services, 2019
2. Cystic Fibrosis Foundation, "About Cystic Fibrosis"
3. Angrawal, A. et al., "Nationwide trends of hospitalizations for cystic fibrosis", 6, 3 (2017):191-198
4. Grosse, SD, et al. "Healthcare expenditures", 53, 12 (2018): 1611-1618
5. Cystic Fibrosis Foundation

Cystic Fibrosis

Then. Now. Imagine.

THEN

In 1962, the median survival age for individuals diagnosed with CF was just ten years.⁶

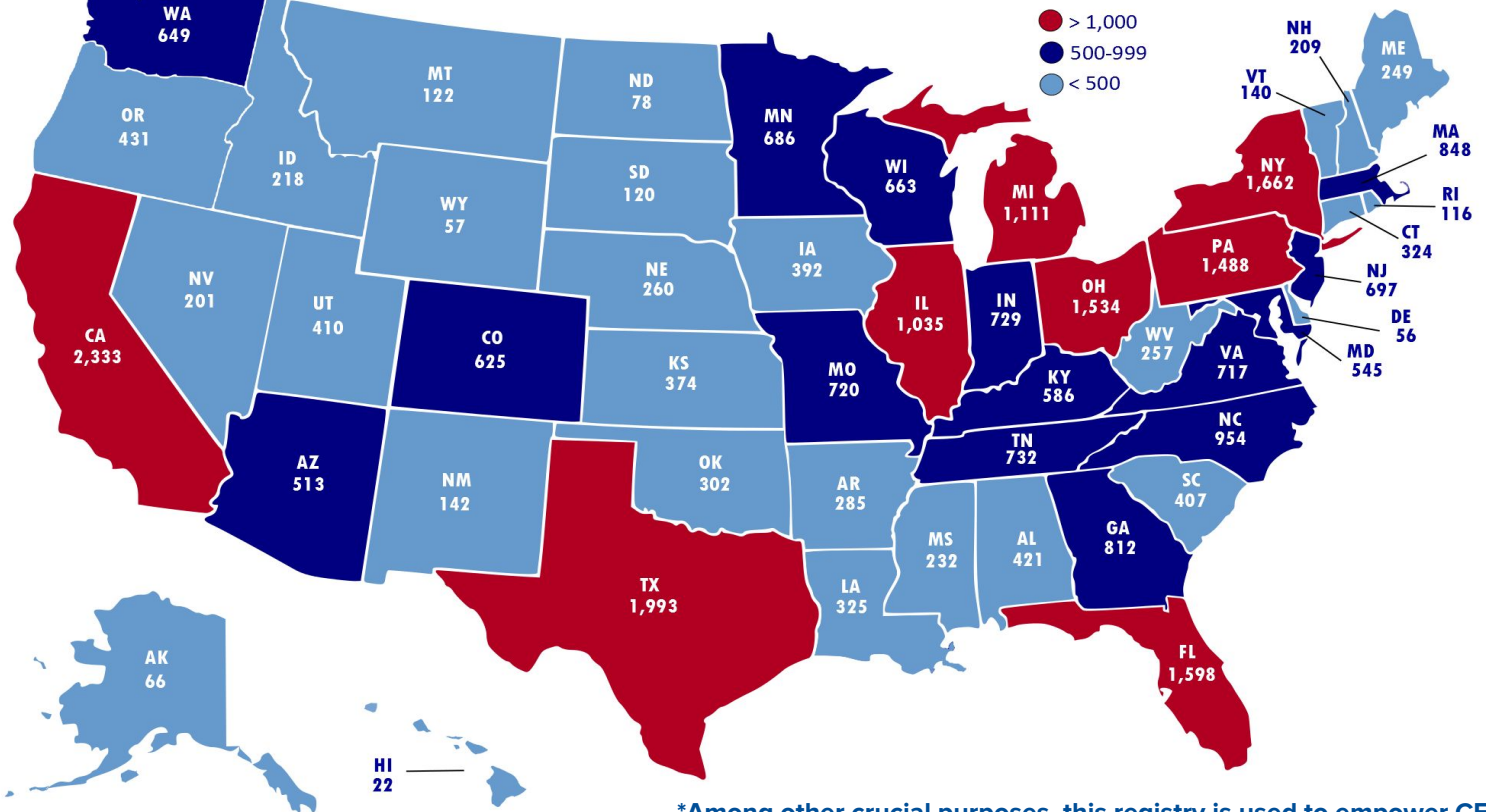
NOW

Thanks to research, the life expectancy of people with CF who are born between 2013 and 2017 is predicted to be 44 years.⁷

IMAGINE

A cure.

Number of individuals enrolled in the Cystic Fibrosis Foundation Patient Registry*, 2016



*Among other crucial purposes, this registry is used to empower CF research, create CF care guidelines, and guide quality improvement care initiatives.

SOURCE: Cystic Fibrosis Foundation

Research!America 241 18th St S, Arlington, VA 22202 | 703.739.2577
www.researchamerica.org | info@researchamerica.org

The Albert and Mary Lasker Foundation is a founding partner in this series of fact sheets. www.laskerfoundation.org

6. National Institutes of Health, "Cystic Fibrosis", 2018
7. Cystic Fibrosis Foundation, "Researcher Resources."
8. Gambling Industry in the US, statista.com
9. NIH Research Portfolio Online Reporting Tools (RePORT)