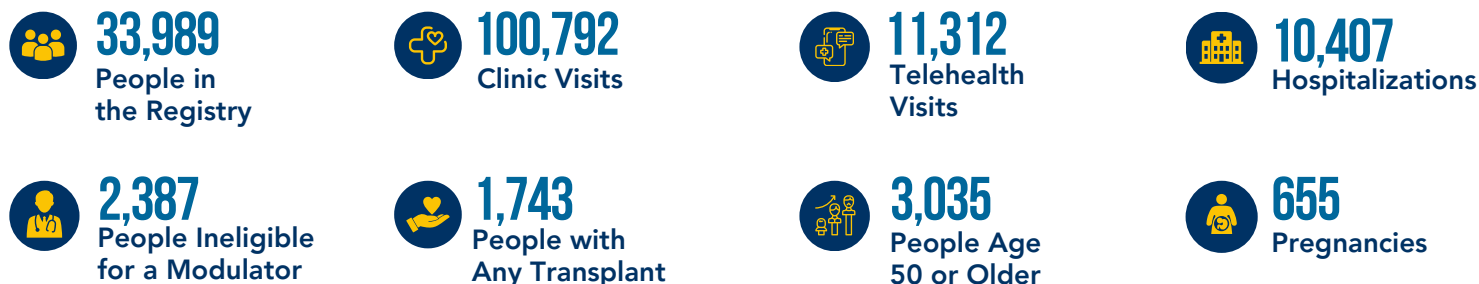


2024 CYSTIC FIBROSIS FOUNDATION Patient Registry Highlights

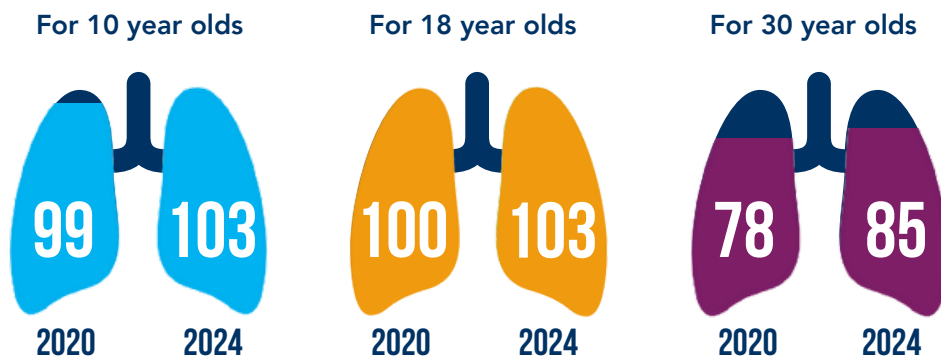
Registry by the Numbers



Lung Function

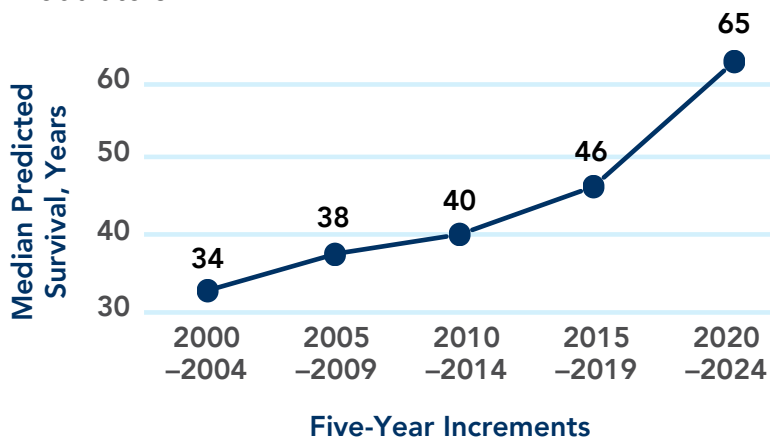
Lung function is a primary indicator of health for people with CF. FEV₁, a measure of lung function, is the forced exhaled volume of air in the first second. It is shown as a percent predicted based on the FEV₁ of healthy, nonsmoking people of the same age, height, and gender.

MEDIAN FEV₁ PERCENT PREDICTED



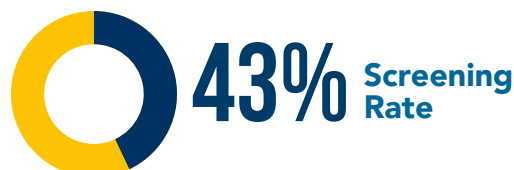
Survival 65 YEARS | 2020–2024

Among people with CF born between 2020 and 2024, half are predicted to live to age 65 or beyond. However, this does not reflect individual variability. The median survival is lower — by possibly more than a decade — for those who are ineligible for CFTR modulators.









Colonoscopy Screenings






People with CF are at higher risk of developing colorectal cancer than the general population.



Common CF Infections

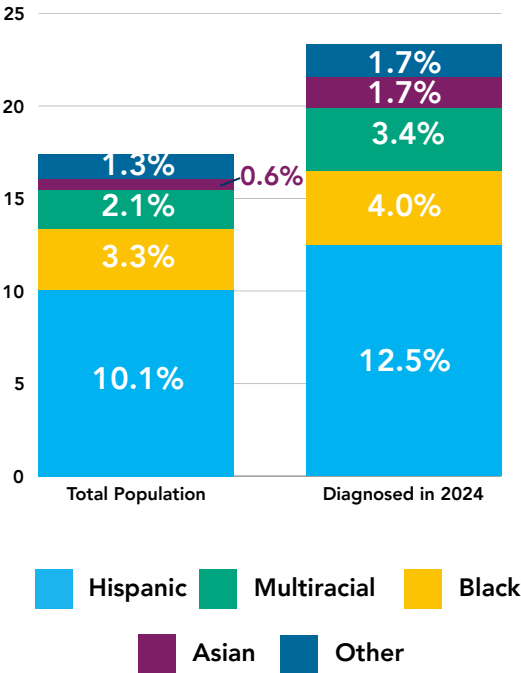
BACTERIA	PERCENT WITH INFECTION	MEDIAN AGE IN YEARS AT FIRST INFECTION
 <i>Pseudomonas aeruginosa</i>	23%	5
 <i>Stenotrophomonas maltophilia</i>	5%	9
 <i>Methicillin-resistant Staphylococcus aureus</i>	13%	10
 <i>Achromobacter xylosoxidans</i>	2%	15
 <i>Burkholderia cepacia complex</i>	1%	20
 <i>Nontuberculous mycobacteria</i>	12%	27

Health Insurance

-  60% of all people with CF are on a private insurance plan.
-  50% of adults with CF 18–25 years are on their parents' insurance plan.
-  13% of adults with CF 18–64 years are on Medicare.
-  36% of all people with CF are on Medicaid.
-  52% of children with CF under 10 years of age are on Medicaid.

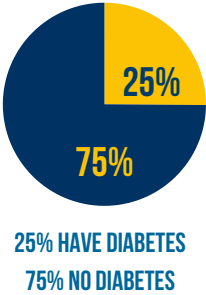
Race and Ethnicity

The CF population is growing more diverse every year. In 2024, more than 23% of people newly diagnosed with CF identified as Hispanic, Black, multiracial, Asian, or another race or ethnicity other than white.



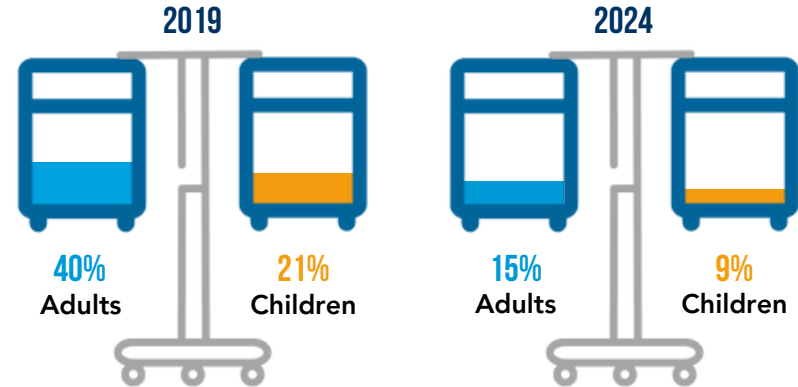
Diabetes in People with CF

In 2024, 24% of people aged 10 or older were identified as having CF-related diabetes. An additional 1% were recorded in the Registry as having Type 1 or Type 2 diabetes.



Exacerbations

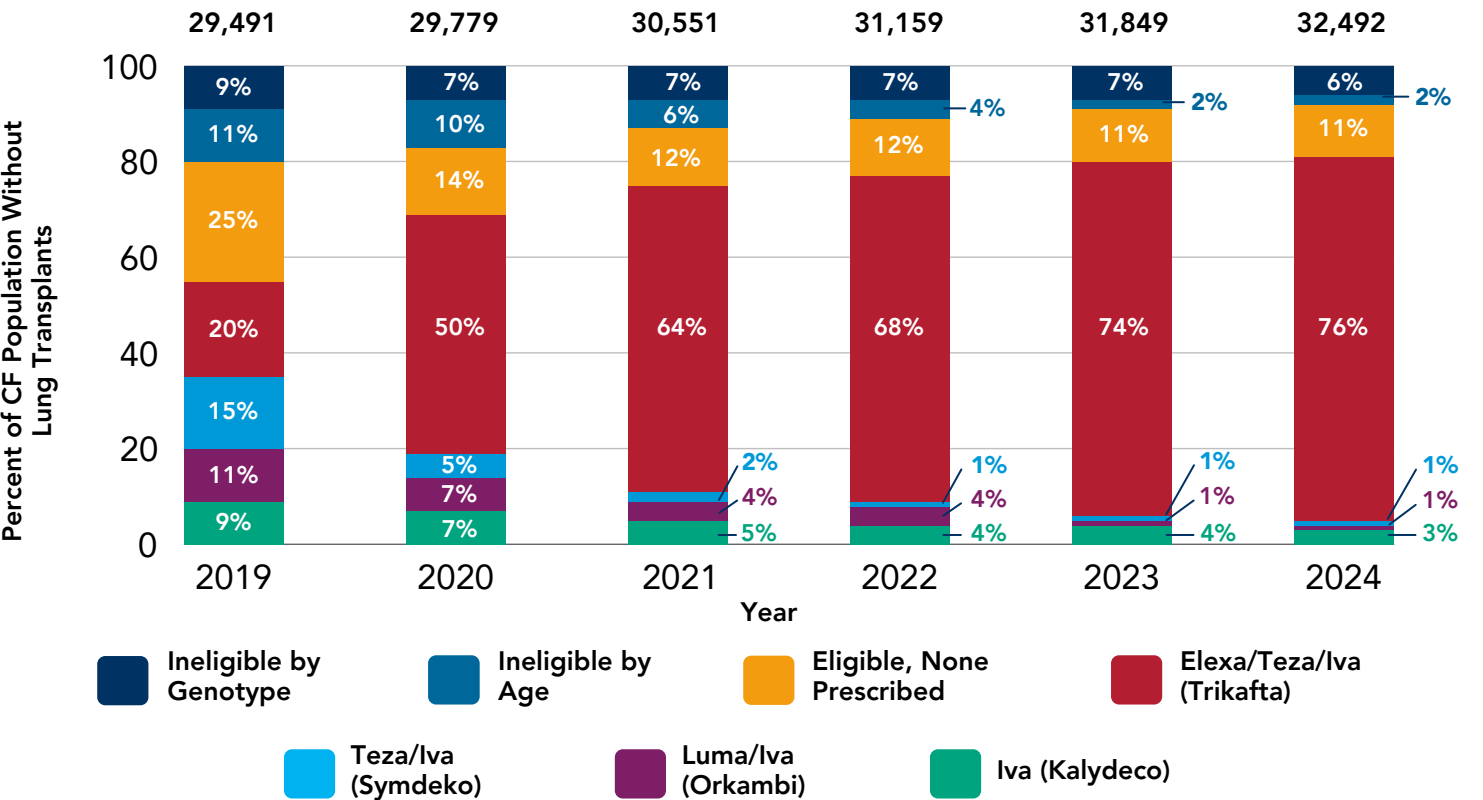
People with CF with One or More Pulmonary Exacerbations
Pulmonary exacerbations (when lung symptoms worsen) may be treated with IV antibiotics. The percent of people with CF treated with IV antibiotics has decreased since 2019.



Use of CFTR Modulators Among People with CF

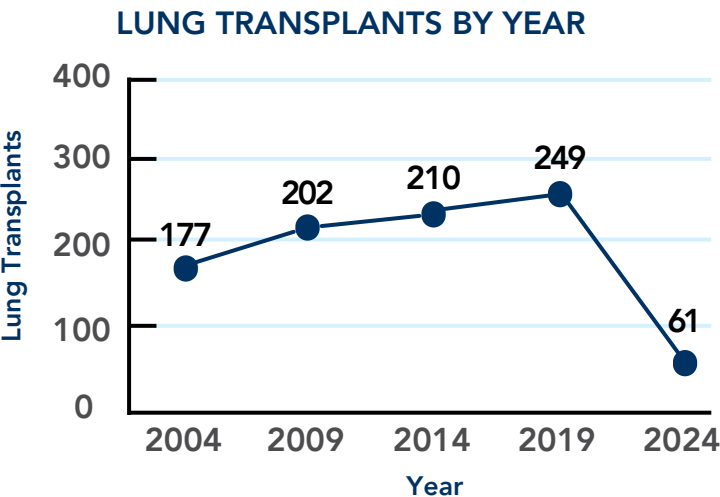
The approval and label expansion of Trikafta led to a significant rise in modulator use among people with CF. The chart also highlights those still not on modulators — either due to age (but may become eligible) or genotype.

Note: 135 people who became eligible after Alyftrek was approved in December 2024 are not included.



Lung Transplants

There has been a dramatic decrease in the number of lung transplants reported compared to the numbers prior to the approval of elexacaftor/tezacaftor/ivacaftor in 2019. In 2024, a total of 61 lung transplants were reported, 19 of which were re-transplants.



Mental Health

Percent of people with CF age 12 years and older with reported depression or anxiety.

DEPRESSION

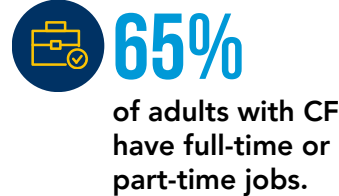


ANXIETY

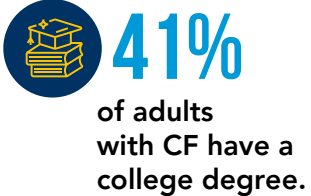


Milestones

EMPLOYMENT

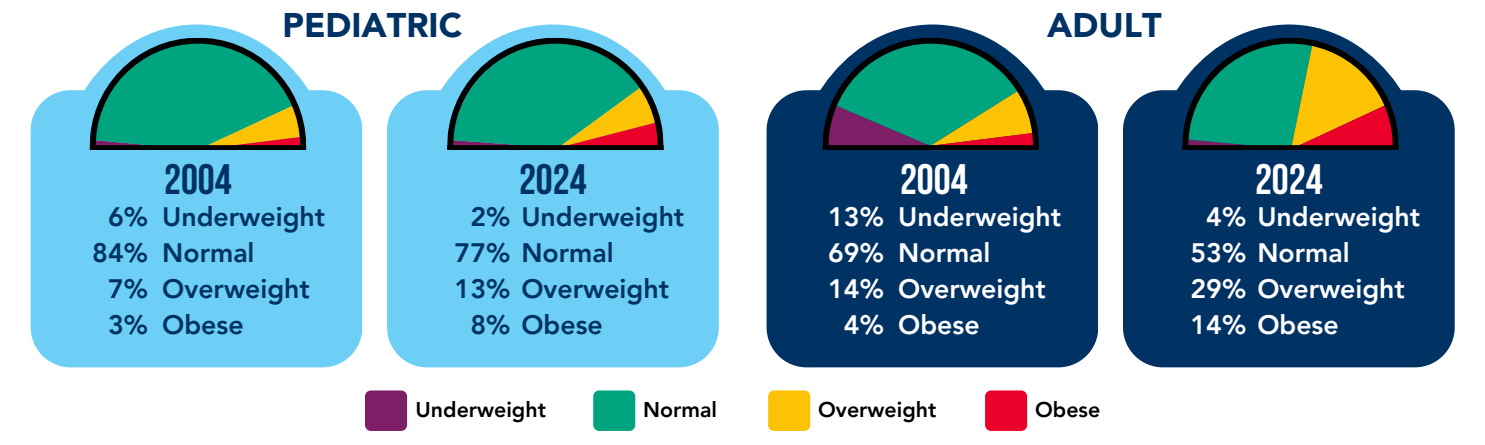


EDUCATION

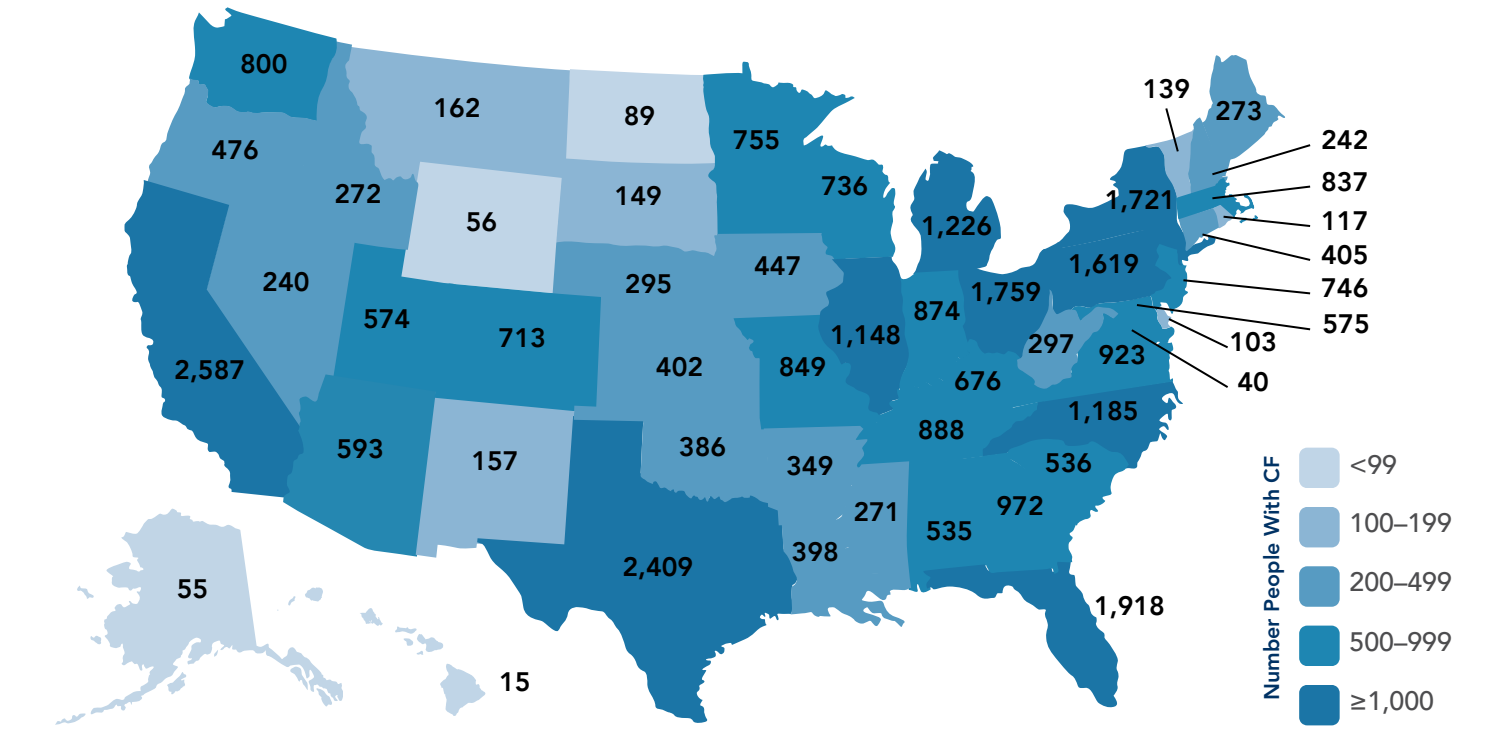


Weight Status Over Time

Over the last 20 years, the percentage of people with CF who are overweight or obese has increased — from 10% to 21% among children with CF and from 18% to 43% among adults.

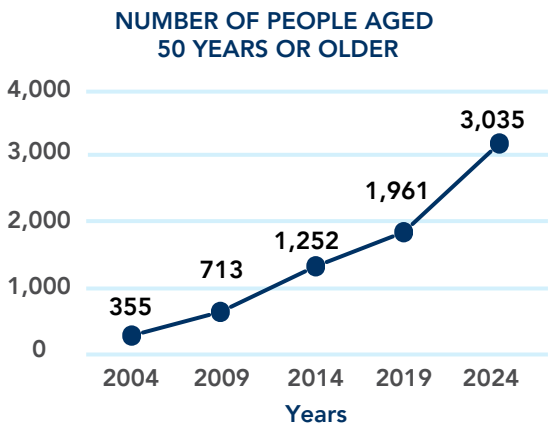


Number of People with CF in the Registry by State



Aging in People with CF

The number of people with CF over the age of 50 is steadily increasing. Advances in care and research, particularly the development of modulator therapies, have dramatically improved life expectancy and quality of life. As a result, more individuals with CF are living longer, healthier lives, transitioning into middle age and beyond — a milestone that was once rare in the CF community.



SOURCE DATA
Cystic fibrosis patients under care at CF Foundation-accredited care centers in the United States, who consented to have their data entered.

SUGGESTED CITATION
2024 Cystic Fibrosis Foundation Patient Registry Highlights
Bethesda, Maryland
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