

2023 CYSTIC FIBROSIS FOUNDATION PATIENT REGISTRY HIGHLIGHTS



REGISTRY BY THE NUMBERS



33,288

People in the Registry



100,648

Clinic Visits



12,569

Telehealth Visits



10,164

Hospitalizations

LUNG FUNCTION

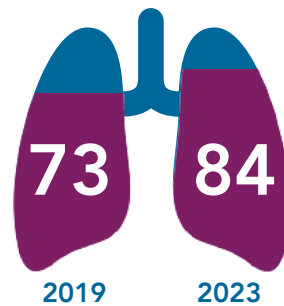
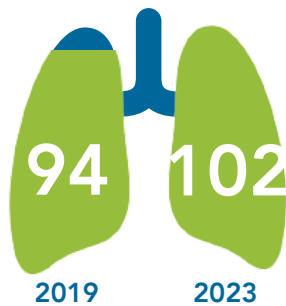
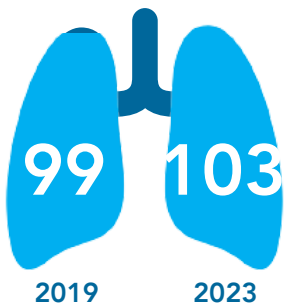
Lung function is a primary indicator of health for people with CF. FEV₁, a measure of lung function, is the forced exhaled volume of air in the first second of an exhaled breath. It is shown as a percent predicted based on the FEV₁ of healthy, non-smoking people of the same age, height, and gender.

Median FEV₁ Percent Predicted

For 10 year olds

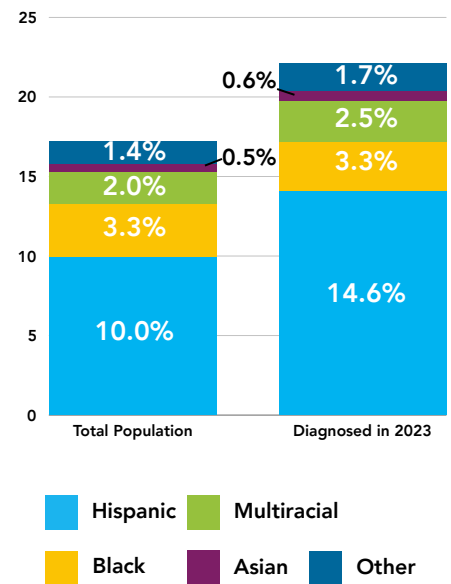
For 18 year olds

For 30 year olds



RACE AND ETHNICITY

The CF population is growing more diverse every year. In 2023, over 17% percent of people with CF identified as either Hispanic, Black, multiracial, Asian or as other than white.



IDENTIFYING CF EARLIER MEDIAN AGE AT FIRST CF EVENT*

2013: 24 days

2019: 22 days

2023: 21 days

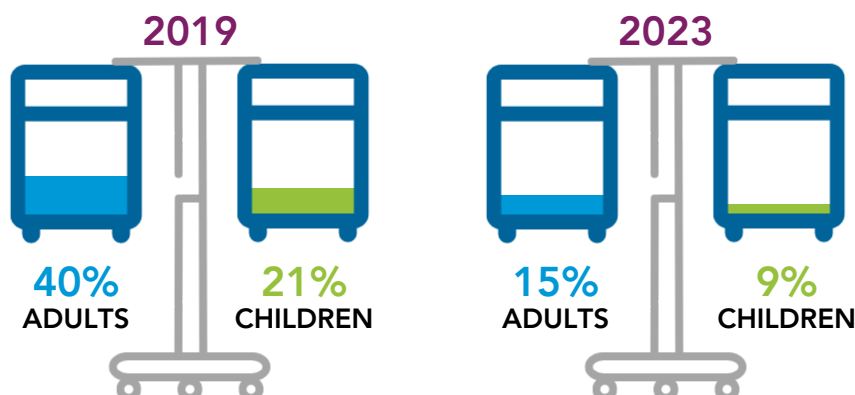


*Measure for timeliness inclusive of sweat test, clinic visit, and/or hospitalization

EXACERBATIONS

PEOPLE WITH CF WITH ONE OR MORE PULMONARY EXACERBATION







Pulmonary exacerbations, when lung symptoms worsen, are common in people with CF. This graphic shows those treated with intravenous antibiotics. Two likely contributors to the decrease since 2019 include the additional attention to infection prevention and control related to the pandemic and the wide adoption of elexacaftor/tezacaftor/ivacaftor.



As Dr. Bruce Marshall steps into retirement in 2024, his legacy with the CF Foundation Patient Registry and contribution to CF care will continue to inspire and guide us.



MICROBIOLOGY

Bacteria	Percent With Infection	Median Age in Years at First Infection
 <i>Pseudomonas aeruginosa</i>	25%	5
 <i>Stenotrophomonas maltophilia</i>	5%	9
 <i>Methicillin-resistant Staphylococcus aureus</i>	14%	10
 <i>Achromobacter xylosoxidans</i>	2%	14
 <i>Burkholderia cepacia complex</i>	1%	20
 <i>Nontuberculous mycobacteria</i>	10%	25

INSURANCE



59% of all people with CF are on a private insurance plan.

49% of adults with CF 18-25 years are on their parents' insurance plan.



13% of adults with CF 18-64 years are on Medicare.

38% of all people with CF are on Medicaid.



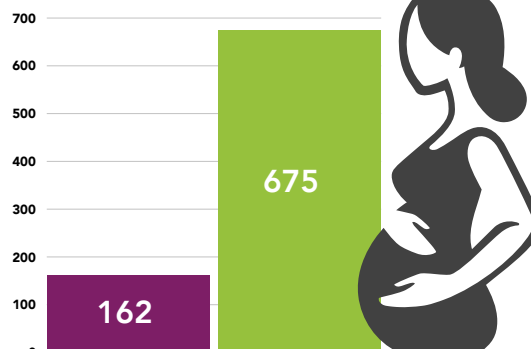
53% of children with CF under 10 years are on Medicaid.

20 YEARS OF PROGRESS

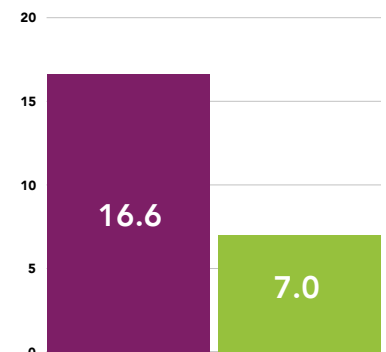
2003 2023



18 Years or Older
2003: 8,518 2023: 20,107

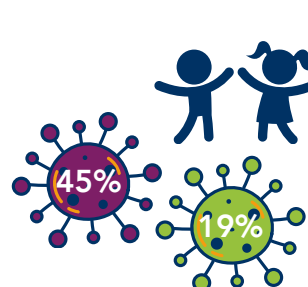
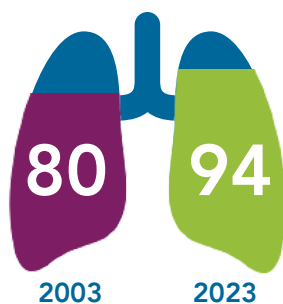


Pregnancies

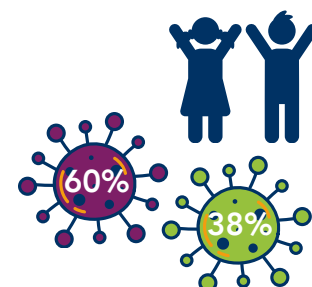


Annual Mortality Rate (Per 1,000 People)

FEV₁ Percent Predicted (Median, individuals 7 years and older)

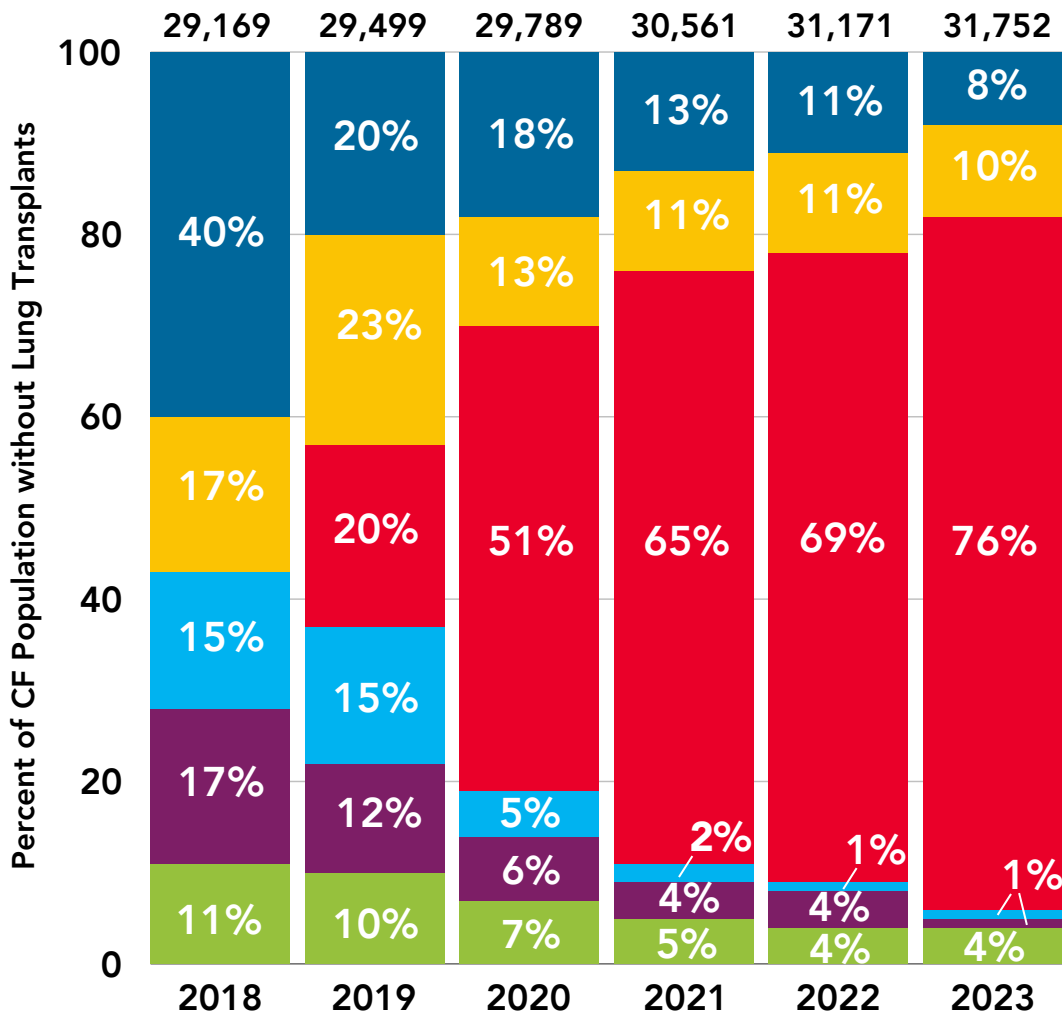


Children on Inhaled Antibiotics



Adults on Inhaled Antibiotics

CFTR MODULATORS

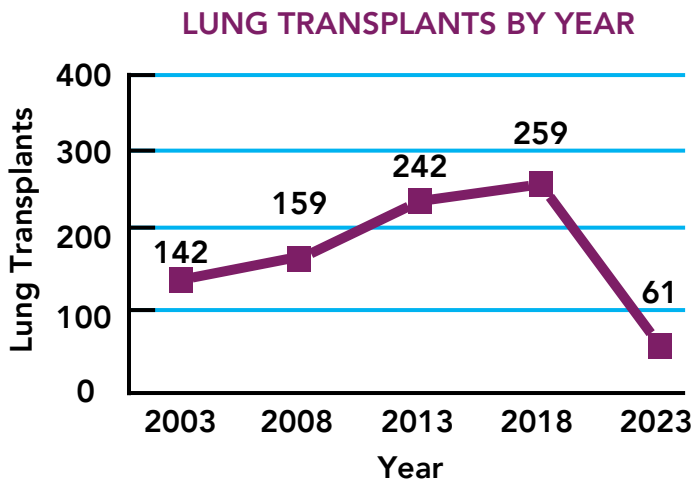


In 2023, 8% of the population was ineligible for a modulator based on their genotype.

- Ineligible by Age or Genotype
- Eligible, None Prescribed
- Elexa/Teza/Iva (Trikafta®)
- Teza/Iva (Symdeko®)
- Luma/Iva (Orkambi®)
- Iva (Kalydeco®)

TRANSPLANTATION

In the Registry, there has been a dramatic decrease in the number of lung transplants reported compared to the numbers prior to the adoption of elexacaftor/tezacaftor/ivacaftor. In 2023, there were 61 lung transplants reported.



MENTAL HEALTH

PERCENT OF PEOPLE WITH CF AGE 12 YEARS AND OLDER WITH REPORTED DEPRESSION OR ANXIETY

26% Depression 28% Anxiety



MILESTONES

EMPLOYMENT



65% of adults with CF have full-time or part-time jobs.

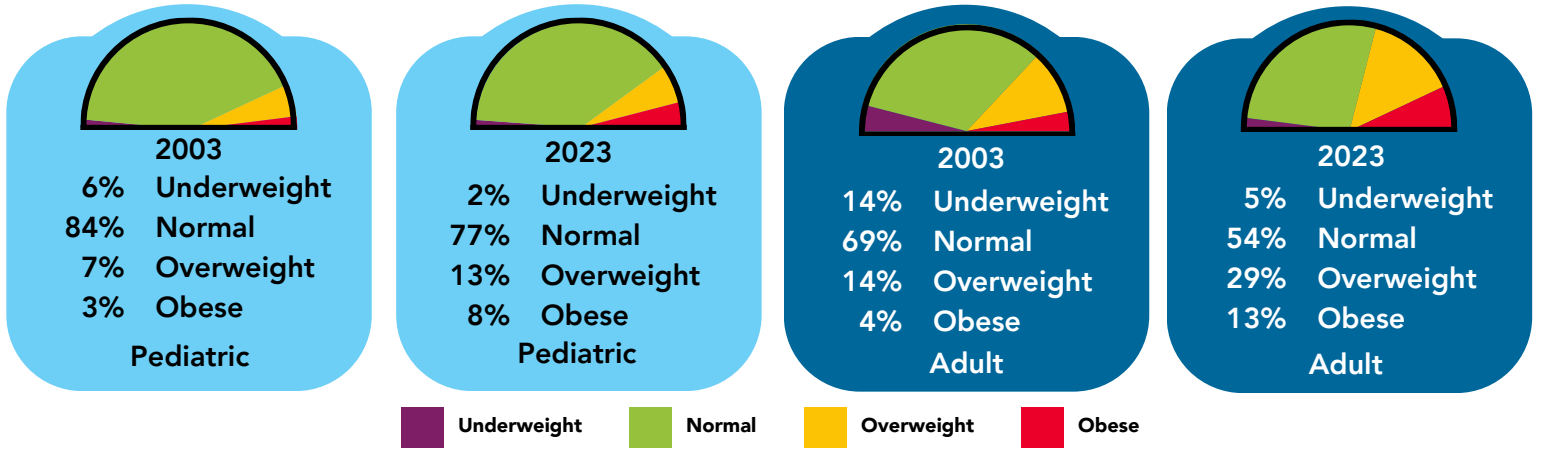
EDUCATION



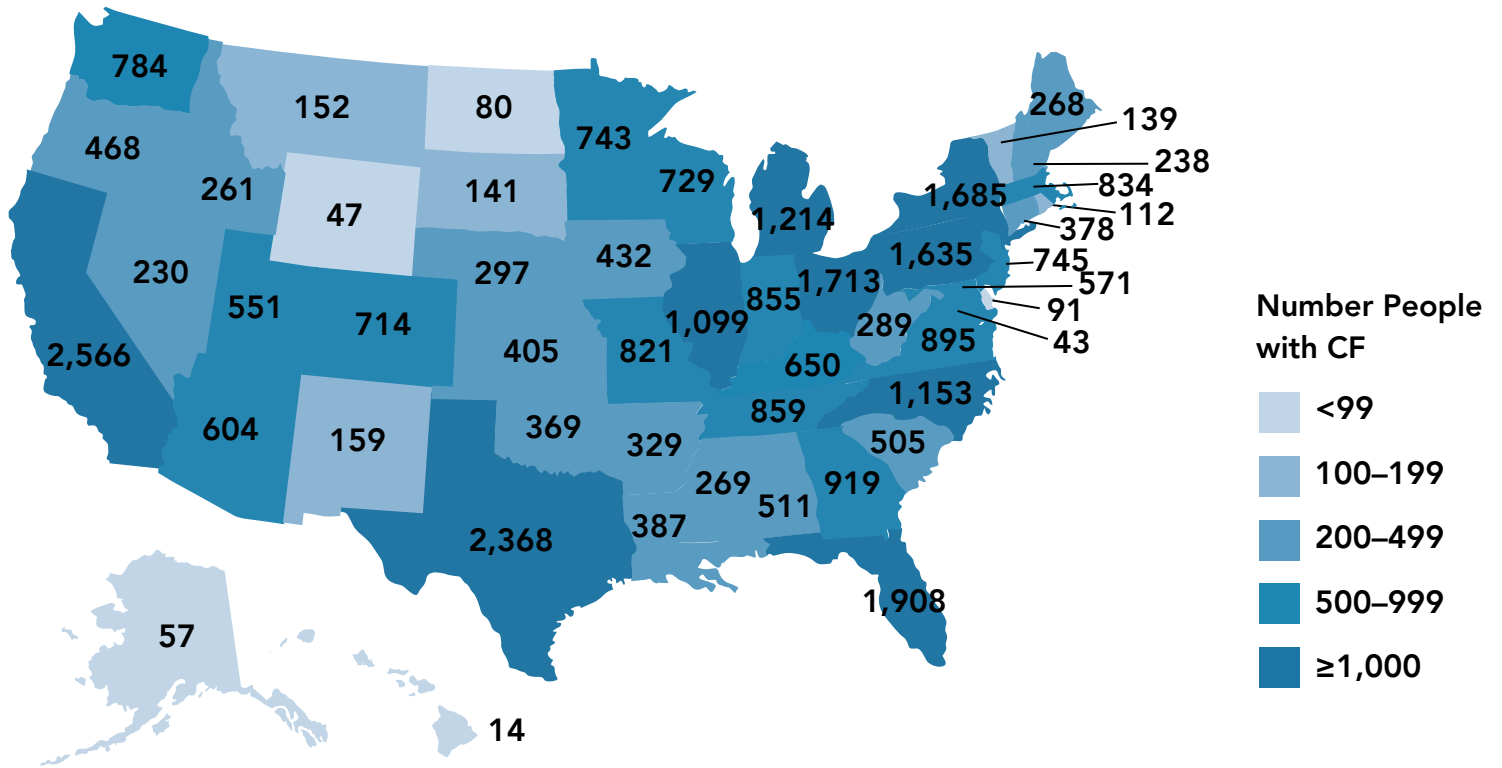
41% of adults with CF have a college degree.

NUTRITIONAL STATUS

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 42% among adults.



NUMBER OF PEOPLE WITH CF IN THE PATIENT REGISTRY



CYSTIC FIBROSIS FOUNDATION
 4550 Montgomery Ave., Suite 1100N
 Bethesda, MD 20814
 800-FIGHT-CF

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
 2023 Cystic Fibrosis Foundation Patient Registry Highlights
 Bethesda, Maryland
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61

YEARS

2019-2023

Among people with CF born 2019-2023, half are predicted to live to 61+ years. However, this does not reflect individual variability. The median survival is lower for those ineligible for modulators by possibly over a decade.

SURVIVAL

