

2019 CYSTIC FIBROSIS FOUNDATION PATIENT REGISTRY HIGHLIGHTS

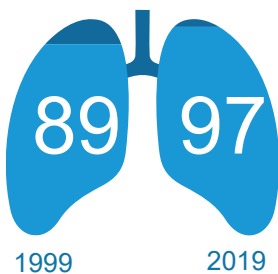


LUNG FUNCTION

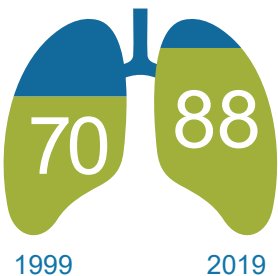
Lung function is a primary indicator of health for people with CF. FEV₁, a measure of lung function, is the Forced Exhaled Volume of air in the first second of an exhaled breath. It is shown as a percent predicted based on the FEV₁ of healthy, non-smoking people of the same age, height, and gender.

Median FEV₁ Percent Predicted

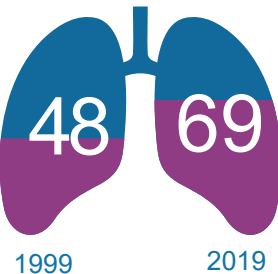
For 10 year olds



For 18 year olds



For 30 year olds



IMPACT OF THE PATIENT REGISTRY

Track
Our Progress



Support
Clinical Trials



Assess
Therapies
After Approval



Improve
Quality of
Care



Facilitate Care
Partnerships



Inform
Clinic and
Telehealth Visits



PATIENT REGISTRY BY THE NUMBERS



289

CF care programs



31,199

People in the Registry



133,116

Clinic visits



21,391

Hospitalizations

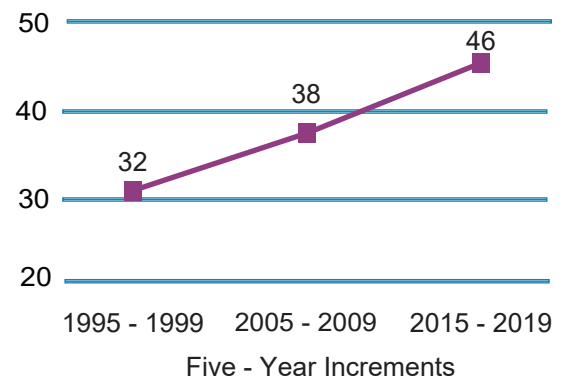
SURVIVAL

46
YEARS

2015 - 2019

Among people with CF born between 2015 and 2019, half are predicted to live to 46 years old or more. This does not reflect individual variability in survival seen among people with CF.

Median Predicted Survival, Years



INSURANCE

CF care is expensive and includes many out-of-pocket costs for outpatient medical care, hospitalizations, and medications. Almost all people with CF have health insurance and many are enrolled in government - funded insurance programs.



54%

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



16%

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



37%

of all people with CF are on Medicaid.



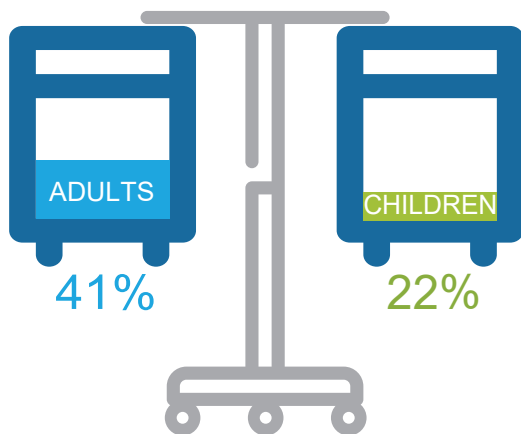
51%

of children with CF under 10 years old are on Medicaid.

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 (IV) antibiotics.



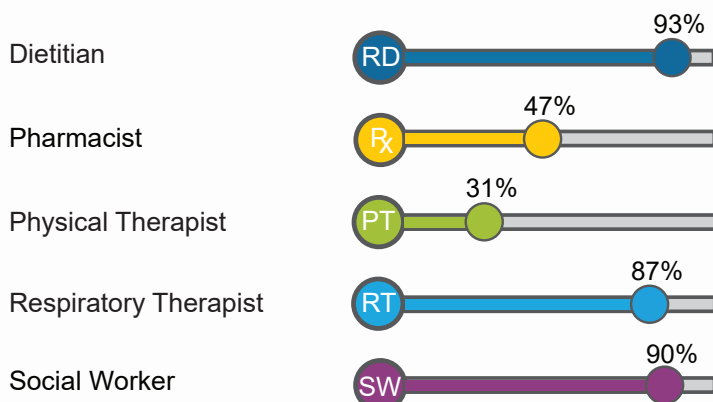
MICROBIOLOGY

Bacteria		Percent With Infection	Median Age in Years at First Infection
<i>Pseudomonas aeruginosa</i>		43%	5
<i>Stenotrophomonas maltophilia</i>		12%	9
Methicillin-resistant <i>Staphylococcus aureus</i>		25%	11
<i>Achromobacter xylosoxidans</i>		6%	14
<i>Burkholderia cepacia</i> complex		3%	20
Nontuberculous mycobacteria		14%	22

People with CF are more vulnerable to lung infections due to the sticky mucus in their lungs. To help prevent the spread of germs, infection prevention and control guidelines were created for clinics, hospitals, homes, schools, and workplaces.

CARE TEAM CONSULTATIONS

PERCENT OF PEOPLE WITH CF SEEN BY EACH SPECIALIST



CF is a complex disease that requires partnership among multidisciplinary teams of health care professionals, people with CF, and their families to provide expert care.

MILESTONES

EMPLOYMENT



53%

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

EDUCATION



39%

of adults with CF have a college degree.

MENTAL HEALTH

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

24% Depression
21% Anxiety



Addressing the mental health of all people with CF is critical to maintaining their overall health and quality of life. Since 2015, the CF Foundation has awarded mental health coordinator grants to care programs to conduct screening and treatment for depression and anxiety.

NUTRITION



Proper nutrition is associated with better lung function.

ADULTS
MEETING BMI GOALS

53%

Over age 20, the BMI (Body Mass Index) goal is 23 for men and 22 for women.

MEDIAN BMI PERCENTILE
FOR 2 - 19 YEAR OLDS

58

The BMI percentile goal is 50 or greater for children and adolescents.

MANIFESTATIONS

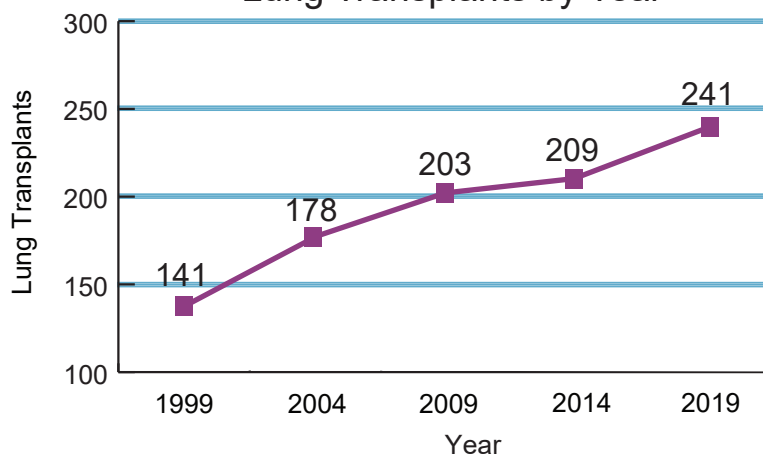
Seen in greater than 10% of the CF Population		Age < 18	Age ≥ 18
Asthma		28%	35%
Acid Reflux		32%	41%
CF - Related Diabetes		5%	31%
Sinus Disease		21%	56%

Some CF manifestations are more common in adults than children. Management of manifestations secondary to CF is important for maintaining an individual's health and quality of life. 94% of people with CF were reported as having one or more manifestations of the disease.

TRANSPLANTATION

Lung transplantation remains an option for some individuals with severe lung disease. The number of lung transplant procedures for people with CF fluctuates yearly, with an overall upward trend. In 2019, there were 1,957 post-lung transplant individuals in the Registry, including 241 individuals who were reported to have received a lung transplant this year.

Lung Transplants by Year

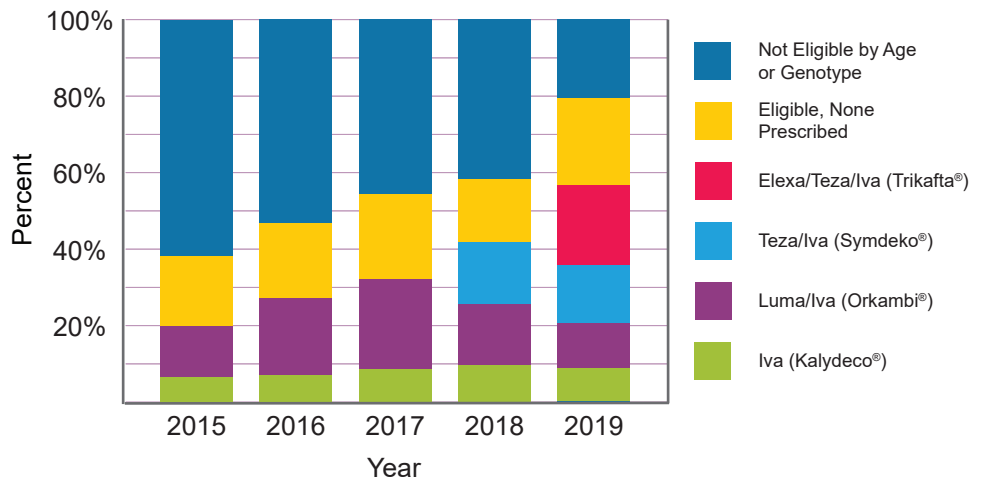


CFTR MODULATORS

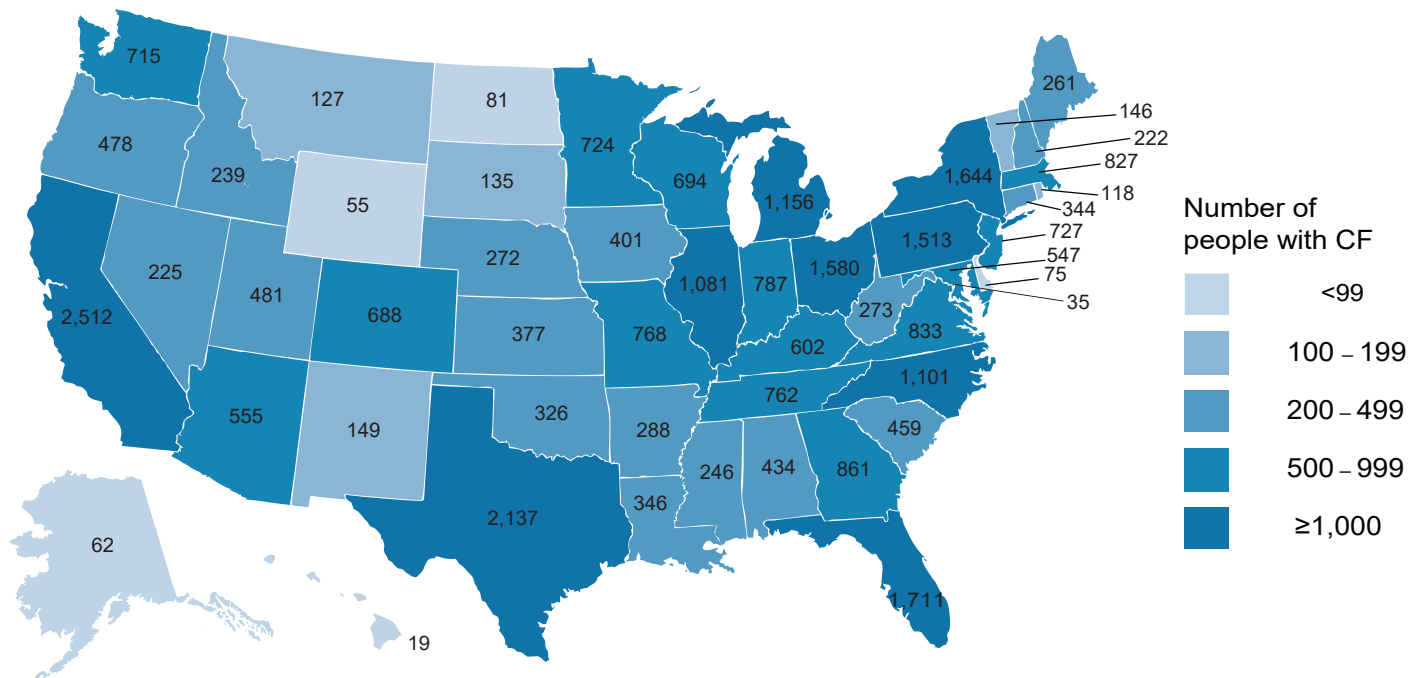
In people with CF, mutations in the CFTR (cystic fibrosis transmembrane conductance regulator) gene can result in a defective protein being produced. CFTR modulators are drugs that improve the function of the CFTR protein.

Approval of triple combo therapy - elexacaftor/tezacaftor/ivacaftor (Trikafta®) - in October 2019, expanded eligibility of people with CF to CFTR modulators. All people, 12 years and older with at least one copy of the F508del mutation became eligible for the therapy. By the end of 2019 and within a couple months of approval, almost 6,000 people with CF were prescribed the new combination therapy.

CFTR MODULATOR BY YEAR



NUMBER OF PEOPLE WITH CF BY STATE



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800-FIGHT-CF

SOURCE OF 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

2019 Cystic Fibrosis Foundation Patient Registry Highlights
Bethesda, Maryland
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97%

of all CF care programs accessed CFSmartReports



15

New study protocols identifying potentially eligible clinical trial participants



84,564

Total number of patient summary reports downloaded

CFSmartReports.com uses CF Foundation Patient Registry data to support care teams in quality improvement and research.