Patient Registry

Annual Data Report 2007

Cystic Fibrosis Foundation | Adding *tomorrows* every day.

Cystic Fibrosis Foundation
...adding tomorrows every day.

The Cystic Fibrosis Foundation's mission is to develop the means to cure and control cystic fibrosis (CF) and to improve the quality of life for those with the disease. We are encouraged by the improvements in CF care shown in this report. We believe that with your help we can make it even better.

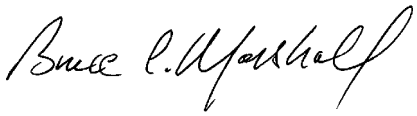
A strong partnership between people with CF, families and healthcare providers working as a team is critical to achieve the best possible health outcomes. Our intention in reporting these data and the health outcomes data from each CF Foundation-accredited care center, available on our Web site (**www.cff.org**), is to educate and help build a strong partnerships between people with CF, their families and care center staff through open communication and information sharing.

We encourage you to use this report and the health outcomes data on the CF Foundation's Web site to start a conversation with your care center staff. Across the country, CF care centers are focusing on quality improvement to improve care, but they need your help. They need your input, your opinions and your involvement. After all, you are the expert in receiving care from a CF center and living with the day-to-day challenges of CF.

Locally, CF care centers have invited people with CF and their families to serve as members of quality improvement teams, act as center advisors, form peer-support groups and share information via newsletters.

We hope you will learn more about what you can do to improve CF care for you or your child and join us in our quest to add tomorrows every day to the lives of those with CF.

Sincerely,



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WHAT IS THE CYSTIC FIBROSIS FOUNDATION PATIENT REGISTRY?

The Cystic Fibrosis Foundation's Patient Registry tracks the health of people with cystic fibrosis (CF) across the United States. The information in this report included data on the more than 24,000 people who receive care at CF Foundation-accredited care centers, and is collected and added to the Patient Registry every year. The collected data includes state of residence, height, weight, gender, genotype, pulmonary function test (PFT) results, pancreatic enzyme use, length of hospitalizations, home IV use and complications related to CF.

Information in the Patient Registry identifies new trends in the health of people with CF, helps create care guidelines, design clinical trials to test new therapies and improve the delivery of care. To make this report comprehensive, it is important for people with CF to agree to have their data in the Patient Registry. The following pages contain information from the Patient Registry including how the health of people with CF is improving, guidelines for care and where more work needs to be done. The CF Foundation's seven goals to accelerate the rate of improvement in CF care are:

1) People with CF and their families are full members of the care team;
2) People with CF will attain normal growth and nutrition status;
3) People with CF will receive early diagnosis of infections and respiratory therapies that help keep lung function steady;
4) To decrease the spread of germs between people with CF;
5) To prevent complications and/or to diagnose and treat them early;
6) To provide care regardless of race, age, education or insurance coverage; and
7) To support all transplantation and end-of-life care decisions.

IF YOU ARE NEW TO CYSTIC FIBROSIS

WHAT IS CYSTIC FIBROSIS?

CF is a genetic disease caused by an abnormal gene. It results in the faulty transport of salt in the body. This leads to thick, sticky mucus that affects the lungs and digestive system. Many people with CF have lung infections and inflammation (swelling). These slowly damage the lungs and their ability to provide oxygen to the body. When the digestive system is affected, it causes problems with the body's ability to absorb food and makes it difficult to grow normally and keep a healthy body weight.

Approximately one in 3,500 children in the United States is born with CF each year. CF affects all racial and ethnic groups. However, it is more common among Caucasians. An estimated 30,000 people in the United States have the disease.

WHAT IS THE CYSTIC FIBROSIS FOUNDATION?

The CF Foundation was created in 1955 by a dedicated group of parents who had children with CF. They had a clear mission — to develop the means to cure and control CF and to improve the quality of life for those with the disease.

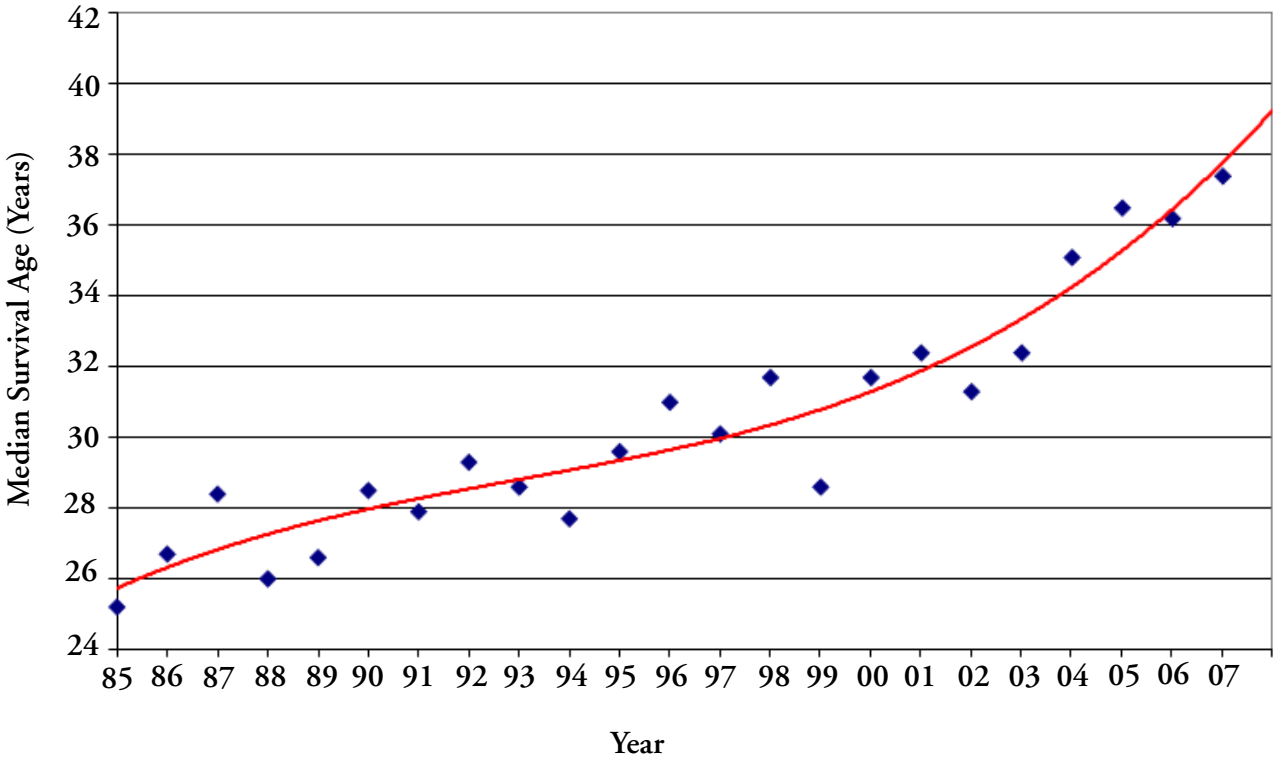
To continue this mission, the CF Foundation has a network of approximately 115 accredited care centers across the United States for people with CF. The CF Foundation provides care centers with grants, training in quality improvement, the latest CF care guidelines based on the medical literature and Patient Registry data to support the care of people with CF. The CF Foundation also provides grants to researchers working to learn more about CF and to discover and develop new therapies to improve the length and quality of life for those with the disease. To learn more about CF and the CF Foundation, visit **www.cff.org**.

SURVIVAL IS IMPROVING

Because of the hard work and strong partnership between people with CF, their families and CF Foundation-accredited care centers, the median predicted survival for people with CF is steadily improving. When the CF Foundation was created in 1955, few children with CF lived to attend elementary school. The graph below shows how much it has improved since 1985. Today, the median predicted age of survival is 37.4 years.

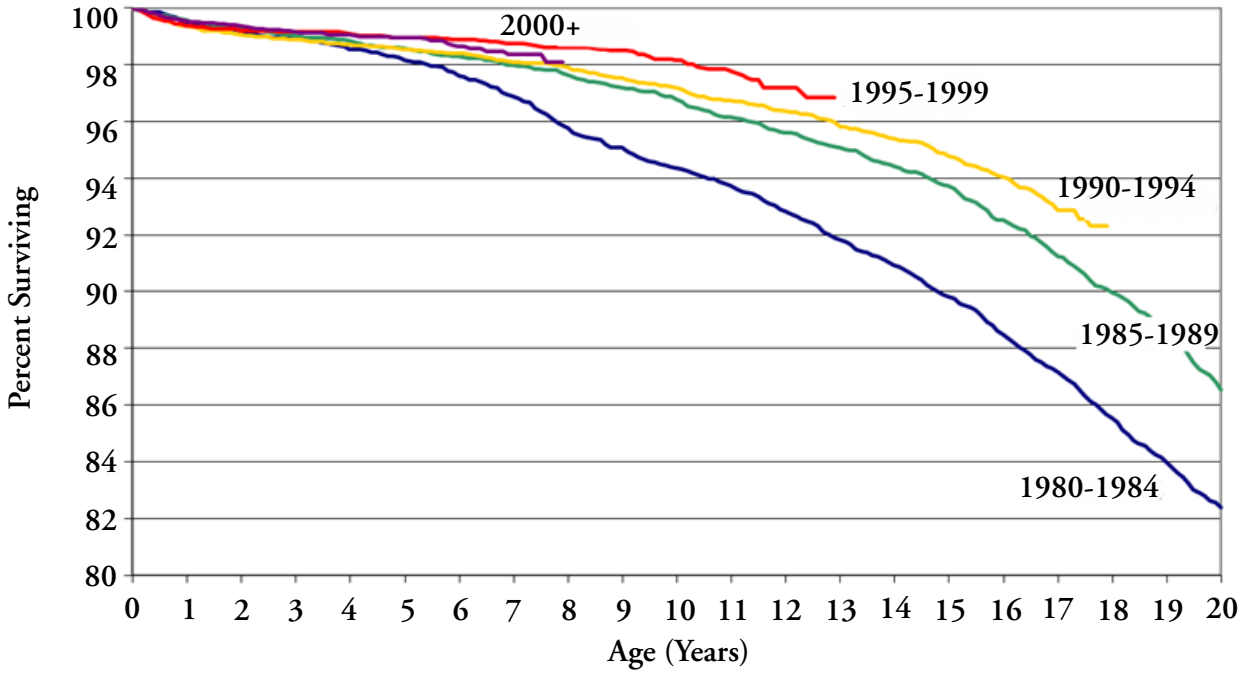
Median age of survival represents the age to which half of the people with CF currently in the Patient Registry would be expected to survive. This number is calculated every year and is based on the deaths that occurred in that year. This continued improvement depends, in part, on gathering and using data from people with CF across the United States through the Patient Registry. The CF Foundation-accredited care centers and the CF Foundation continue to partner with people with CF and their families to keep this number increasing.

Median Predicted Survival Age, 1985-2007



The graph at the top of the next page is another way to show that survival continues to improve. Of people with CF born between 1980 and 1984 (dark blue line), 90.2 percent were alive at age 15. For children born between 1990 and 1994 (yellow line), 95.2 percent were alive at age 15. The CF Foundation has been working with all 50 states in an effort to have all newborn babies screened for CF. The earlier CF is diagnosed, the sooner treatment can be started to slow the disease and hopefully prevent complications. Earlier diagnosis and treatment is one way to improve the quality and length of life for those with CF.

Survival from Age One by Birth Cohort



Goal 1: People with CF and their families are full members of the care team. Communication will be open so everyone can be involved in decisions about care. Care will be respectful of patients' needs, preferences and values.

Through the Patient Registry, care centers get data about their patients and the combined health of people with CF in the United States. These reports help care centers talk with their patients and families about some of the important aspects of the disease. One report is the "Patient Summary Report" on the next page. It shows trends in lung function, nutrition and other important information about the person with CF. Ask your CF care center for a copy of your or your child's "Patient Summary Report" at your next CF clinic visit.

Another report has key health data for each of the accredited CF care centers. This report is on the CF Foundation's Web site under "Care Center Network" (**www.cff.org**). The purpose of this data is to encourage people with CF and their families to get involved with their care center to improve CF care. This data is updated every year. We encourage you to start a conversation with your care center about your center's data. The following questions are good to ask. What does the data mean? How can I help improve my or my child's health? What can I do to help my center improve? Partner with your care center and be a full and active member of your CF care team.

The CF Foundation's Patient Registry Annual Data Report shows health trends of people with CF in the United States. To learn more about this data and how to work with your care center, watch the archived Web casts "One Team's Story: Raising the Bar for CF Care" and "Quality CF Care Is More Than the Numbers" on the CF Foundation's Web site (**www.cff.org/LivingWithCF/Webcasts/**). You can also read the success stories of how others work with their care centers to improve care in the Quality Improvement section of the CF Foundation's Web site (**www.cff.org/LivingWithCF/QualityImprovement/**).

Patient Report Example:

VISIT DATE: _____
Last Hospitalization: 1/18/ - 1/23/
Last HomeIV Therapy: 1/23/ - 2/3/
Last Clinical Visit: 12/18/

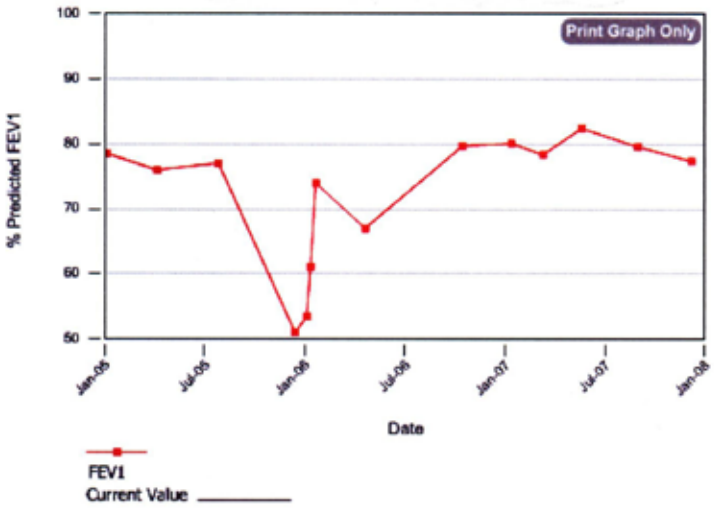
Name:
Date of Birth:
Genotype: Date Unknown ^F508 / ^F508

Culture Results

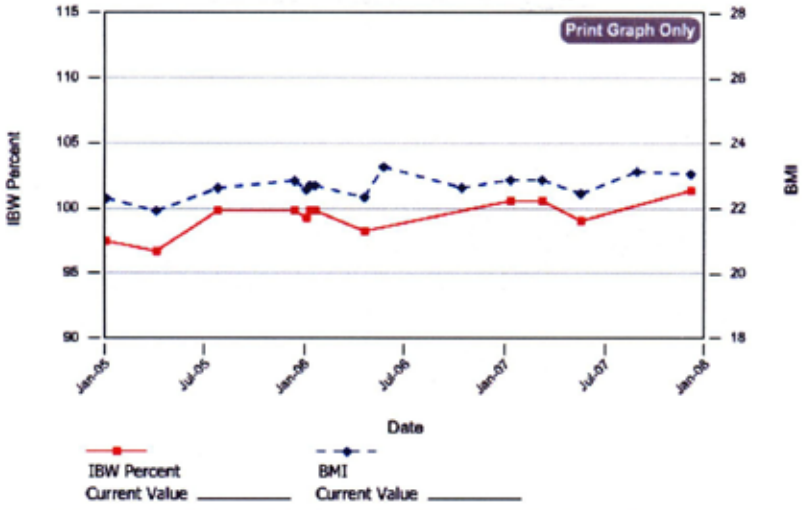
Last Culture: Pseudomonas aeruginosa, Staphylococcus aureus, : 9/11/

Last Positive:	B. cepacia	MRSA	PA	MDR-PA+
	None	10/26/	9/11/	9/11/

PFT Trend



Nutritional Trend



Complications

ACTIVE @ LAST VISIT

- CFRD
- Dist Int Obst Synd (DIOS)
- Peptic ulcer disease
- Sinus Disease (symptomatic)

COMPLICATIONS PREVIOUSLY NOTED

- CFRD
- Dist Int Obst Synd (DIOS)
- Peptic ulcer disease
- Sinus Disease (symptomatic)

Routine Evaluations

Last PFT: 12/18/
Last CXR: 2006
Last SW Visit: 4/6/

Last Dietary Visit: 6/6/
Last LFT: 9/11/
Glucose Screening: 10/19/
Creatinine: 9/11/

GUIDELINES FOR CF CARE

The CF Foundation gathers CF health experts to review the medical literature, research on CF care and data from the Patient Registry to develop guidelines for the care of everyone with CF. Below is an overview of how people with CF in the Patient Registry met guidelines for CF care in 2007.

Guidelines for CF Care	Children Who Meet Guidelines (%)	Adults Who Meet Guidelines (%)
Clinic Visits — 4 or More Per Year	72.4	58.9
Pulmonary Function Tests — (PFT) 2 or More Per Year	84.4	81.0
Respiratory Cultures — At Least 1 Per Year	95.3	90.3
Glucose — Every Year if ≥14 Years	76.5	72.5
Liver Enzymes — Every Year	77.7	76.8
Influenza (flu) Vaccine — Every Year if ≥ 6 Months of Age	72.4	61.7

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MAINTAINING NORMAL NUTRITION

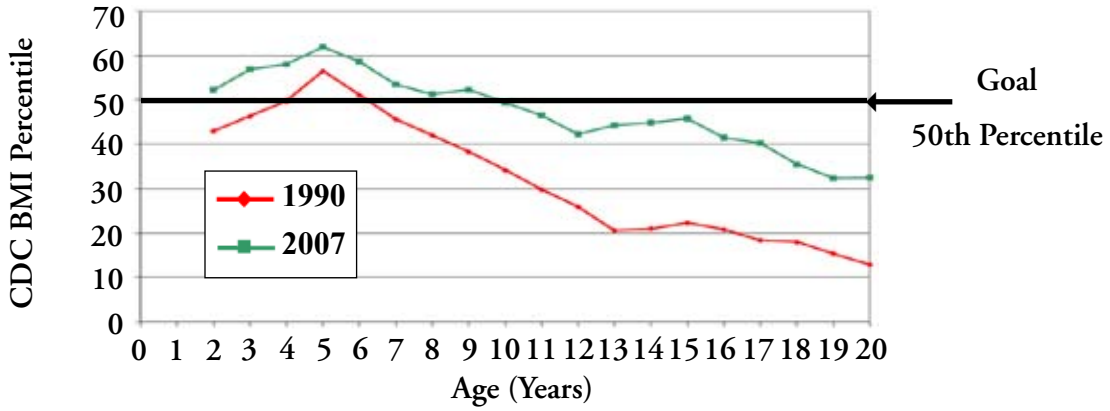
Goal 2: Children and teens will have normal growth and good nutrition. Adults' nutrition will be maintained as near to "normal" as possible.

The nutrition of people with CF is getting better, but more work remains. In 2005, the CF Foundation worked closely with experts in CF and nutrition to develop nutrition care guidelines and to set national body mass index (BMI) goals for people with CF. BMI is based on a person's weight and height. It is used to screen for people who may have health problems if the BMI is too high or too low. For children and teens, BMI is stated as a percentile compared to children without CF of the same age and gender.

BMI is calculated by dividing body weight in kilograms by the person's height in meters squared (weight kg/height m^2=BMI). You can calculate your BMI or your child's BMI percentile on the Centers for Disease Control and Prevention's Web site (www.cdc.gov/nccdphp/dnpa/healthyweight/assessingbmi/index.htm).

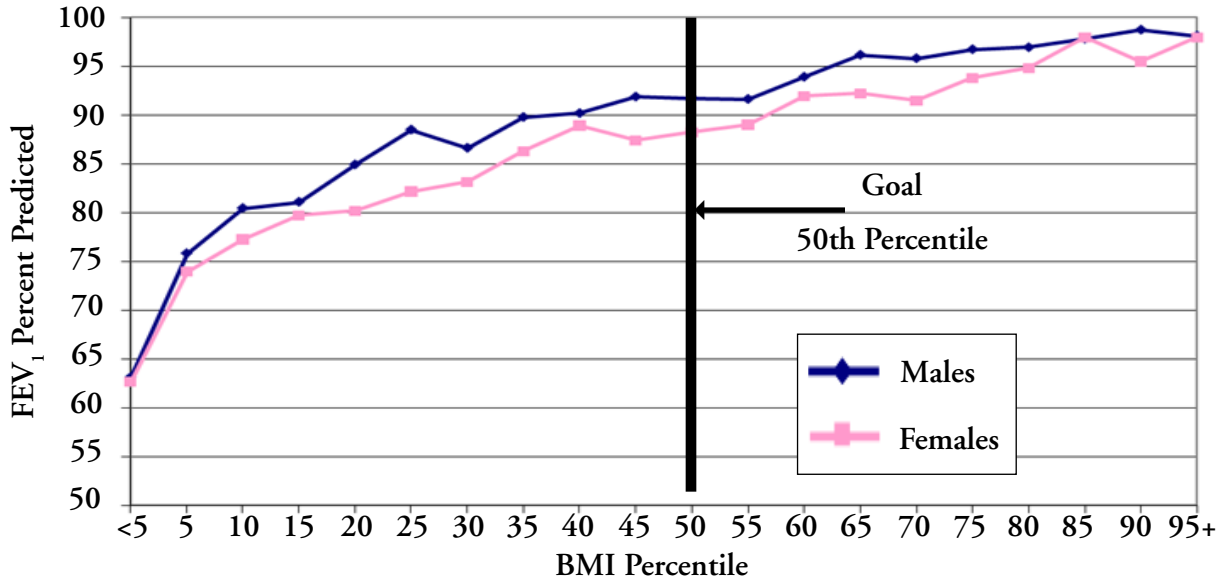
The goal is for children to be around the 50th BMI percentile for their age, which is the average BMI percentile for children in the United States who do not have CF. We want children with CF to grow and develop like children without CF. The graph on the top of the next page shows how much the BMI percentile of children with CF has improved since 1990.

Median CDC BMI Percentiles vs. Age, 1990 and 2007*



The Patient Registry shows a strong connection between a higher BMI percentile and better lung function in children. Lung function is measured by FEV_1 or Forced Expiratory Volume over one second. This is shown as percent predicted based on healthy, non-smoking people of the same gender and age. The graph below shows that good nutrition and lung health seem to go hand in hand. The highlighted bar is the BMI percentile goal for children with CF.

FEV_1 Percent Predicted vs. BMI Percentile in Children 6-20 Years*

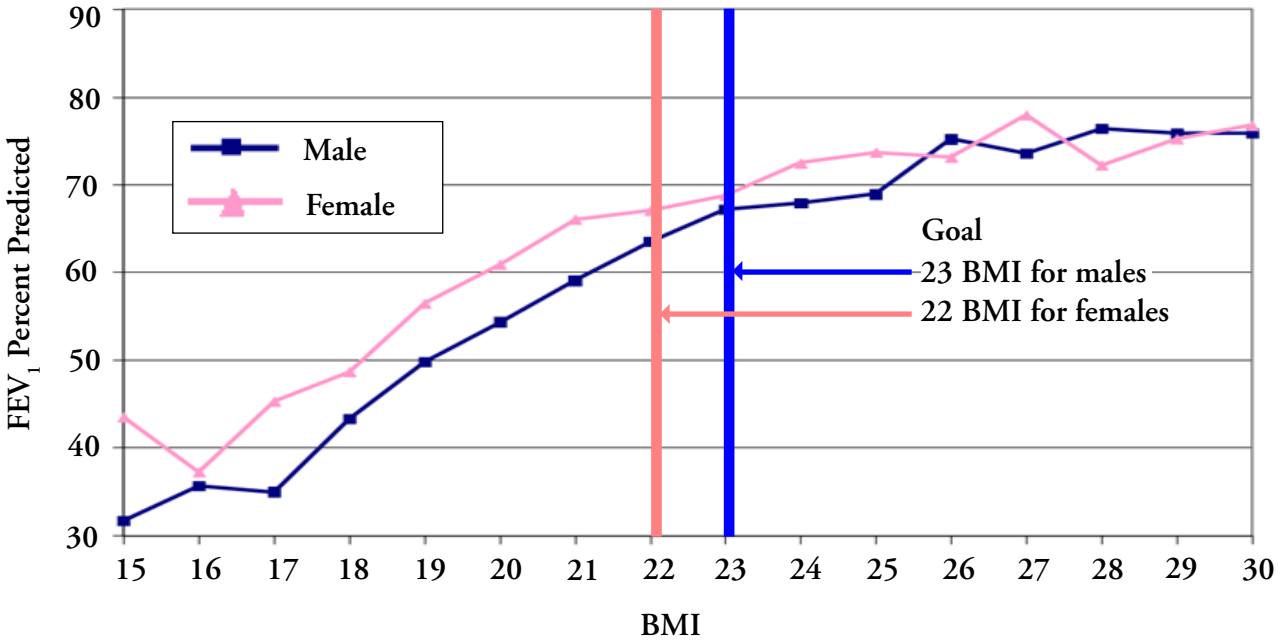


The connection between a higher BMI and better lung function is also seen in adults with CF. Highlighted on the graph at the top of the next page are the national BMI goals for men and women with CF. For men, they should partner with their care center for a BMI of 23 and for women a BMI of 22.

Work closely with your CF care center to improve and/or maintain your or your child's weight. To learn more about CF and nutrition, ask your CF care center or visit the CF Foundation's Web site (**www.cff.org**) to read or watch an archived Web cast about CF and nutrition.

* Centers for Disease Control and Prevention — **www.cdc.gov/nccdphp/dnpa/healthyweight/assessingbmi/index.htm**

FEV$_1$ Percent Predicted vs. BMI in Adults 20 to 40 Years by Gender*

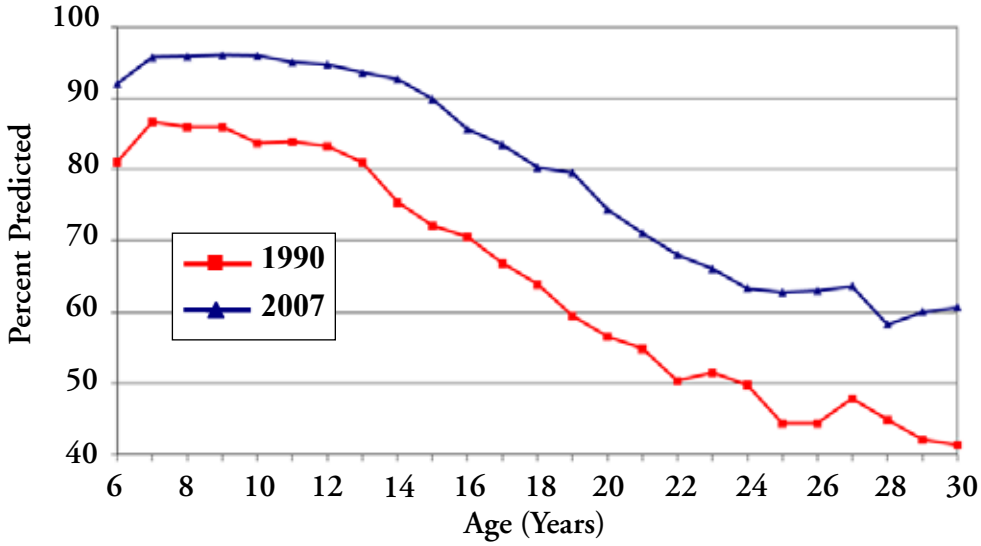


LUNG FUNCTION

Goal 3: Everyone with CF will receive the right therapies to keep lung function steady and to decrease the number of pulmonary exacerbations or respiratory infections. Exacerbations will be diagnosed early and treated appropriately.

The graph below shows that there have been major improvements in the lung health of people with CF since 1990. FEV$_1$ (lung function) is usually near normal or just under 100 percent predicted when first measured around 6 years of age.

Median Percent Predicted FEV$_1$ vs. Age, 1990 and 2007

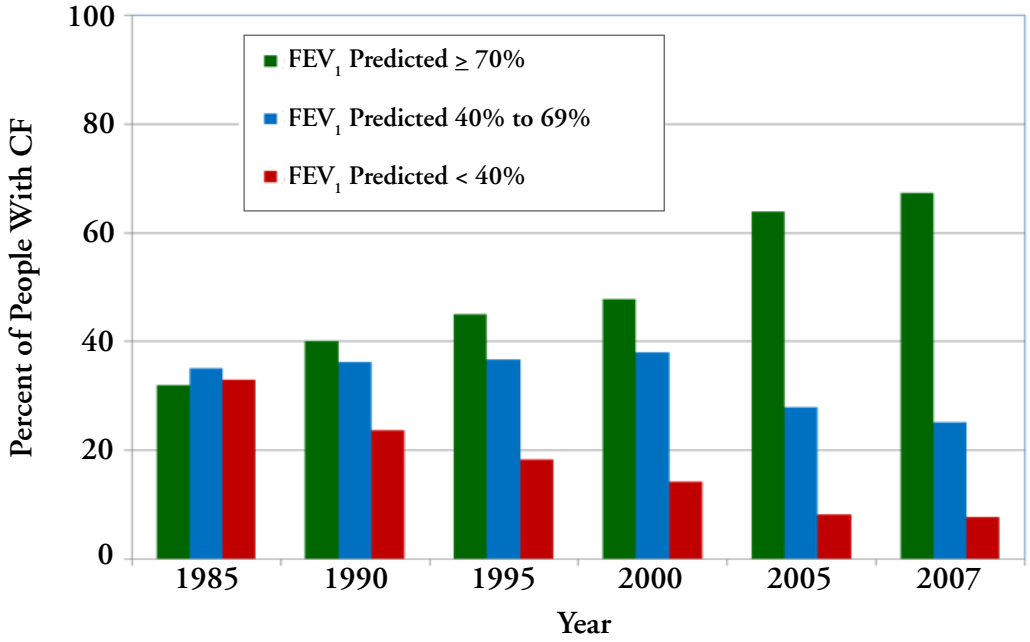


* Centers for Disease Control and Prevention — **www.cdc.gov/nccdphp/dnpa/healthyweight/assessingbmi/index.htm**

Severity of lung disease is based on a person's FEV_1 percent predicted. In CF, the lower a person's FEV_1 the more severe the lung disease. An FEV_1 greater than or equal to 90 percent is normal. An FEV_1 between 70 and 89 percent means the person has mild lung disease. An FEV_1 between 40 and 69 percent indicates moderate lung disease. If the FEV_1 is less than 40 percent, severe lung disease is present.

The graph below shows an increase in the percentage of 18 year olds with CF in the Patient Registry with normal lung function or mild lung disease. The rising number of people with normal lung function or mild disease, and the decreasing number with severe disease, show that the lungs of people with CF are much healthier now than 20 years ago.

Respiratory Severity in 18 Year Olds, 1985 to 2007



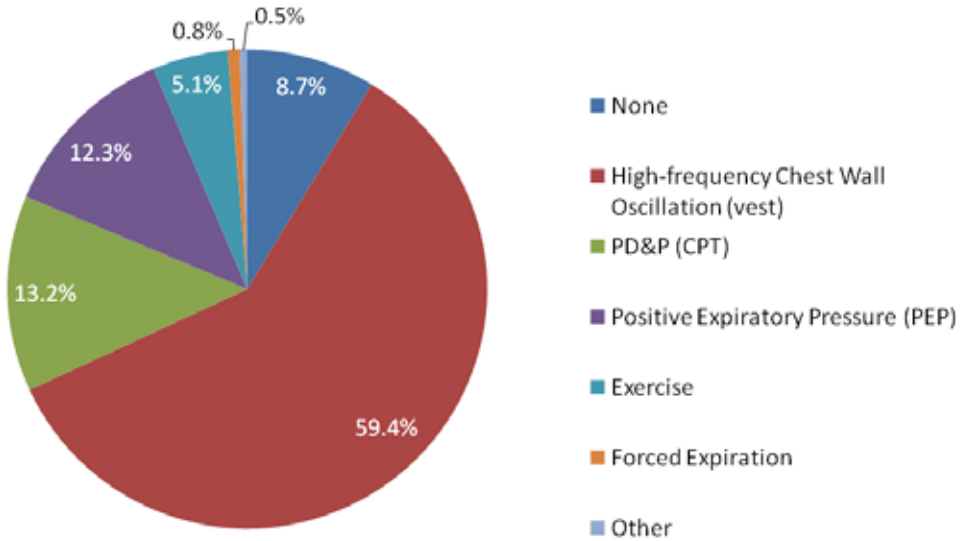
In 2007, the "Cystic Fibrosis Pulmonary Guidelines: Chronic Medications for Maintenance of Lung Function" was published in the November edition of the *American Journal of Respiratory and Critcal Care Medicine*. The guidelines were developed by experts in CF lung disease who reviewed research data and recommended medications to help people with CF maintain lung health. These therapies are for people who meet certain criteria (e.g., age, severity of disease).

The table on the next page shows the criteria for medications to help maintain lung function, and the percentage of people with CF who are taking each medication. Talk to your CF doctor to find out if you or your child might do well on one of these medications. The CF Foundation is supporting research to find ways that CF centers can partner with people with CF and their families to get and use the right medicines regularly.

Medication	Percentage (%) of people who fit the criteria and are on the medication	Criteria for medication
tobramycin (TOBI®)	66.5	• ≥ 6 years of age • Positive for *P. aeruginosa* • Moderate to severe lung disease
rhDNase (Pulmozyme®)	74.0	• ≥ 6 years of age
azithromycin (Zithromax®)	63.3	• ≥ 6 years of age • Positive for *P. aeruginosa* • Moderate to severe lung disease • Weight ≥ 55 pounds (25kg)
ibuprofen	4.6	• 6-12 years of age • Moderate to severe lung disease
hypertonic saline	34.2	• ≥ 6 years of age

Medicines are only one way to help keep CF lungs healthy. Getting the thick CF mucus out of the lung is also important. Airway clearance therapies (ACT) move CF mucus out of the lungs. The body's normal and most basic ACT is coughing. It is a reflex, which clears mucus with high-speed airflow. Sometimes mucus cannot be cleared with coughing alone. There are many different airway clearance therapies that people with CF can use to help keep their lungs clear of extra mucus. The method of ACT you use varies by care center and person. In 2007, the CF Foundation gathered experts in CF lung health to look at the latest research related to ACT and set the ACT guidelines for CF care. Experts noted that people with CF should do ACT to keep their lungs healthy, even when they are not sick. The method used can vary, but it is important that ACT be done daily. The chart below shows the percentage of people with CF who use various ACT as the main way to clear the mucus from their lungs. You can learn more about ACT on the CF Foundation's Web site (**www.cff.org/treatments/Therapies/**).

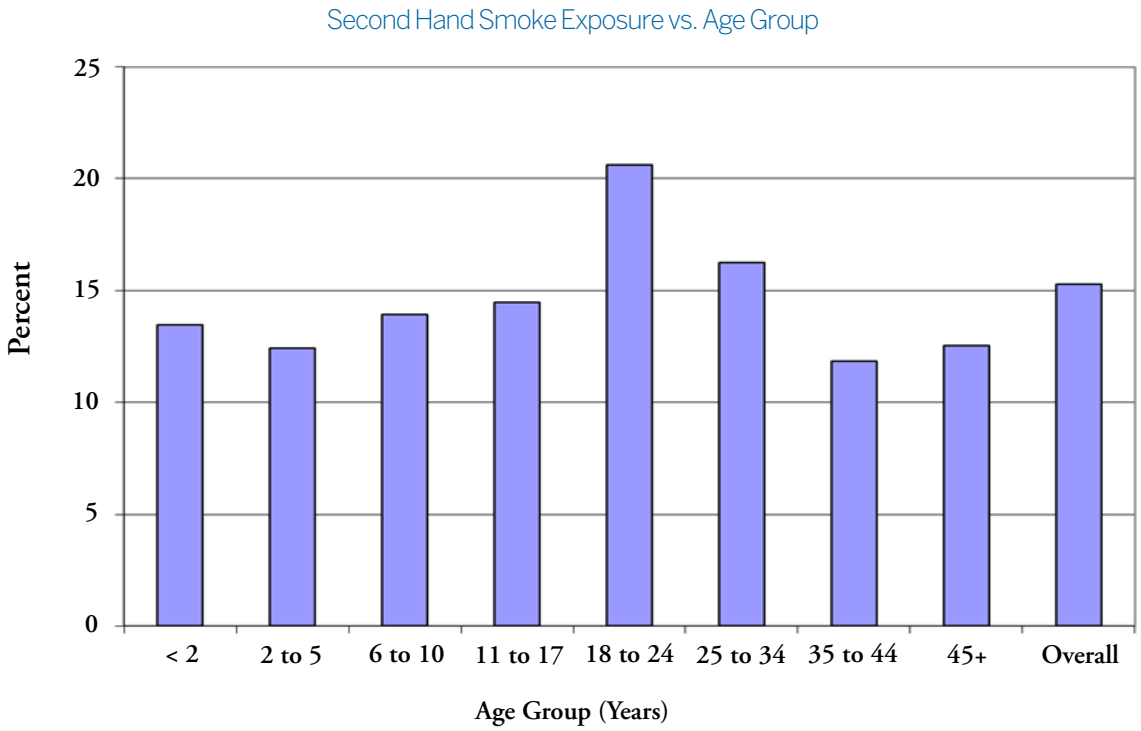
Main Method of Airway Clearance Therapy (ACT)



Each time a person with CF has a respiratory infection or exacerbation, there may be lung damage. However, there are things you can do to prevent or lessen the chance of a lung infection, such as:

- Doing airway clearance to keep your lungs as clear as possible of mucus;
- Taking the medicines as prescribed by your CF doctor;
- Getting a flu shot every fall for you or your child and everyone living in the house;
- Regular exercise to strengthen your muscles;
- Avoiding germs by using good hand hygiene and properly cleaning and disinfecting equipment; and
- Avoiding secondhand smoke exposure.

The graph below shows, by age group, the percentage of people with CF who breathe in secondhand smoke. Secondhand smoke comes from burning tobacco in cigarettes, cigars, pipes and the smoke breathed out by people who smoke. It has been shown that children who breathe in secondhand smoke have more respiratory infections. In adults who do not smoke, breathing in secondhand smoke can cause lung cancer and heart disease. The Surgeon General has concluded that breathing even a little secondhand smoke can be harmful.



The only way to fully protect yourself and your child from secondhand smoke is to be in 100 percent smoke-free environments.

You can:

- Make your home and car smoke-free.
- Ask people not to smoke around you or your child.
- Teach your child to stay away from secondhand smoke.
- Make sure that your child's day care center or school is smoke-free.
- Choose restaurants and other businesses that are smoke-free. Thank businesses for being smoke-free. Let owners of businesses that are not smoke-free know that secondhand smoke is harmful to your family's health.

If you are a smoker, the single best way to protect your family from secondhand smoke is to quit smoking. In the meantime, only smoke outside to protect your family. A smoke-free home rule can also help you quit smoking. Your doctor can help you quit smoking.

For more information, please refer to "How to Protect Yourself and Your Loved Ones from Second-hand Smoke" available at **www.cdc.gov/tobacco**.

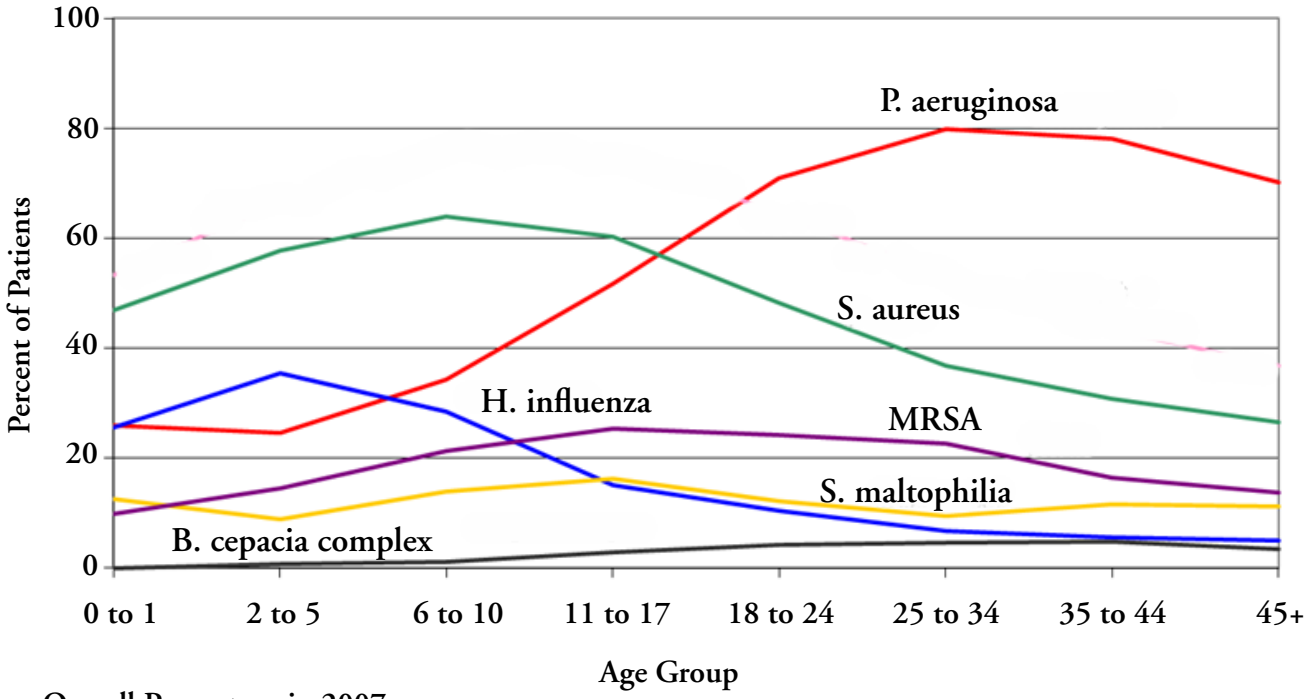
Even if you are careful and do all you can to prevent a lung infection, it is hard to avoid infections totally. If you or your child start to feel ill (e.g., increased cough, loss of energy or appetite), call your care center so treatment can be started as soon as possible.

To learn more about lung care and therapies for people with CF, visit the "Living With Cystic Fibrosis" section of the CF Foundation's Web site (**www.cff.org**). Also, you can watch archived Web casts about CF lung health and disease. It is important that you and your CF care center work together to create a plan to maintain your or your child's health.

Goal 4: People with CF and their care centers will work together to eliminate the chances of getting respiratory pathogens or germs, particularly Pseudomonas aeruginosa (P. aeruginosa) and Burkholderia cepacia (B. cepacia) complex, in the hospital, clinic and home.

Repeated lung infections or exacerbations are a concern for people with CF. It is the cycle of infection and inflammation (swelling) that damage the lungs. This damage causes lung function (FEV_1) to decline. When the lungs are damaged, infections happen more often. The next graph shows some of the germs that are found in the lungs of people with CF. The best way to avoid germs is to do good hand hygiene with soap and water or alcohol hand gels. Talk to your CF care center to learn more about how to prevent respiratory infections. Information about what CF germs are, how they are spread and a Web cast on "How to Avoid Germs" is available in the "Living With Cystic Fibrosis" section of the CF Foundation's Web site (**www.cff.org**).

Respiratory Infections vs. Age



Overall Percentage in 2007:

- P. aeruginosa 54.4%
- H. influenza 17.1%
- B. cepacia 2.9%
- S. aureus 51.4%
- S. maltophilia 12.6%
- MRSA 21.2%

COMPLICATIONS OF CF

Goal 5: People with CF will be closely monitored for complications of CF, especially CF-related diabetes (CFRD). Prevention and early treatment of any CF complication is the goal.

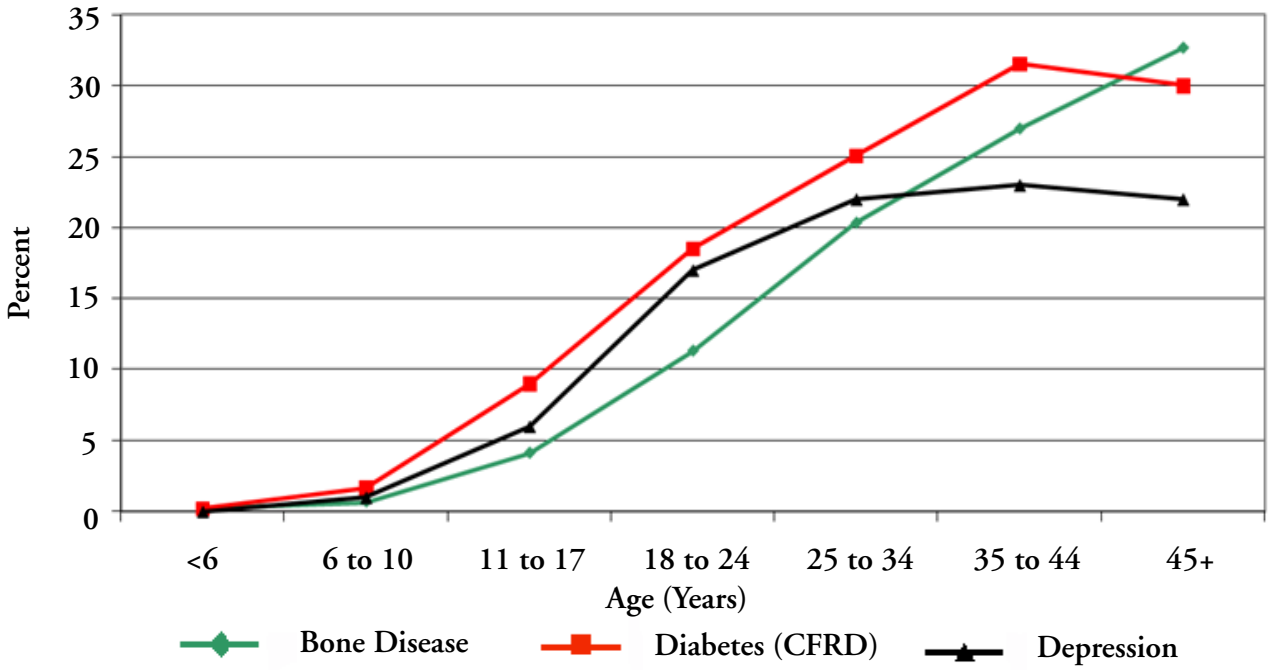
In the early 1990s, data in the Patient Registry showed an increase in the number of teens and adults with diabetes. CFRD is different from diabetes in people without CF because cystic fibrosis damages the pancreas. Anyone with CF, 14 years of age and older, should be tested every year for CFRD. Data suggest that early diagnosis and treatment of CFRD results in better nutrition and weight gain and thus, better health. The CF Foundation continues to fund CFRD research. To learn about CF Foundation-supported research, visit **www.cff.org**.

The Patient Registry shows trends in other complications of CF as well. The importance of good nutrition and healthy bones is often in the news. Data from the Patient Registry show that about 10 percent of people with CF had bone disease in 2007. Preventing or lessening bone disease begins in childhood when bones are growing. Good nutrition, a healthy weight and exercise can help. Ask your CF dietitian what can be done to keep your or your child's bones healthy.

Another finding from the Patient Registry is that almost 20 percent of adults with CF have symptoms of depression. Also, this is a common complication found in other chronic diseases. People with CF, their families and caregivers need to be aware of this complication, so that diagnosis and treatment can be started early. People often respond well to treatment for depression.

Gastroesophageal reflux (GERD), asthma and sinus disease are some of the other complications people with CF may experience. The CF Foundation continues to promote prevention, early diagnosis and treatment of common complications.

Common Complications vs. Age



ACCESS TO CARE

Goal 6: Everyone with CF will be able to receive appropriate therapies, treatments and support regardless of race, age, education or insurance coverage.

Research suggests that people with CF who live in households with lower incomes are more likely to have lower lung function and lower BMI or BMI percentile. This pattern of poor health in lower-income households is also common in other chronic diseases. The CF Foundation is working to find out why this happens in CF and how to change it. CF Services Pharmacy, a mail-order pharmacy and wholly owned subsidiary of the CF Foundation, works hard so proven CF therapies are available to everyone. They run CF-specific patient assistance programs to help people with CF get CF medications. Go to their Web site to learn more (**www.cfservicespharmacy.com**).

Data from the Patient Registry show that therapies like Pulmozyme® and TOBI® are available to people with CF, no matter their income. You can learn more about your legal rights and hear how

others manage CF by watching the archived Web casts "Patient Advocacy: Issues and Answers" and "Building Life Skills to Manage CF," available in the "Living With Cystic Fibrosis" section of the CF Foundation's Web site (**www.cff.org**).

Learn more about race and age of the people in the Patient Registry on page 18, "A Summary of the 2007 Data."

Insurance Coverage 2007

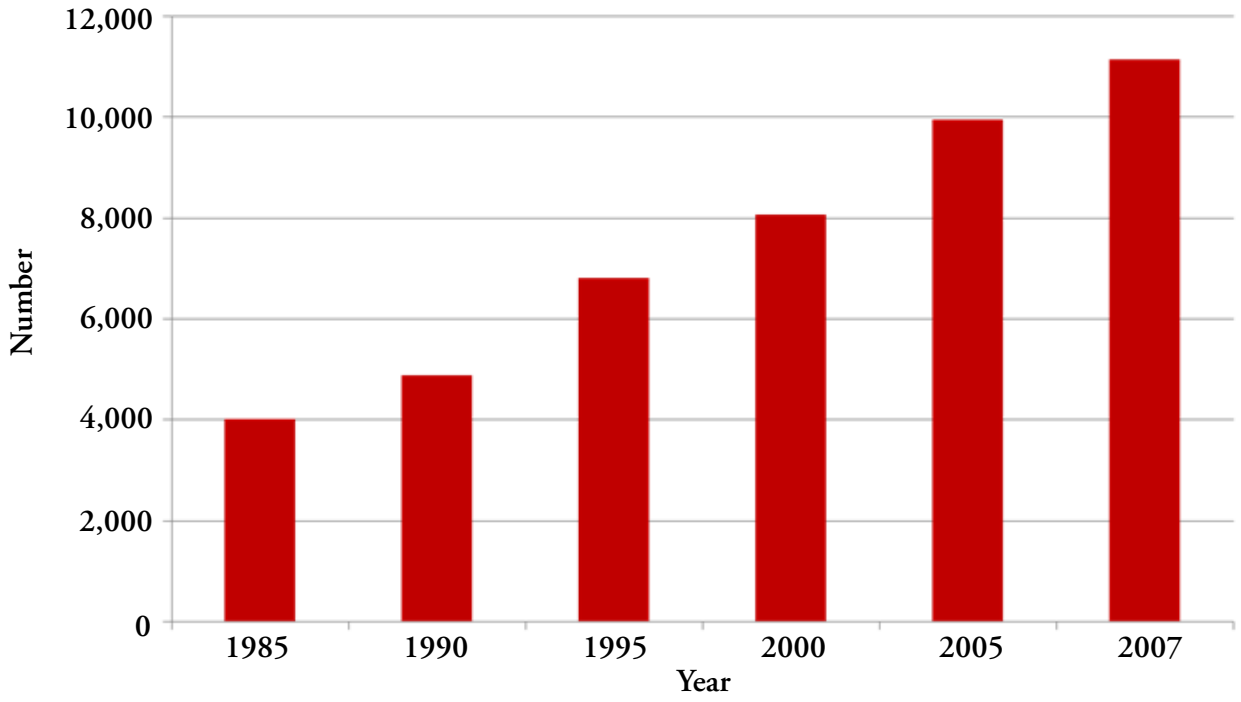
Type of Insurance*	Children <18 Years (%)	Adults ≥ 18 Years (%)
No Insurance	2.1	4.5
Private/HMO	61.0	65.6
Medicaid/State	47.5	33.4
CHAMPUS	1.8	1.4
Federal	0.9	12.7
Other	2.4	2.5

*Data are not mutually exclusive, as people with CF may have more than one type of insurance.

ADULTS WITH CF

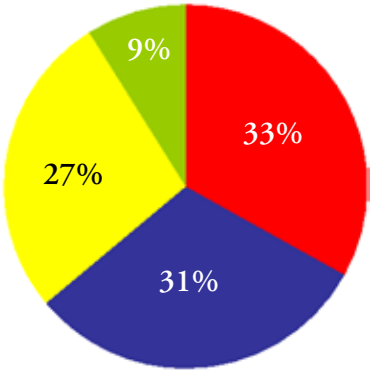
In 1990, about 30 percent of people in the Patient Registry were age 18 or older. In 2007, more than 45 percent of people with CF in the Patient Registry were adults, and that number continues to grow.

Number of Adults With CF



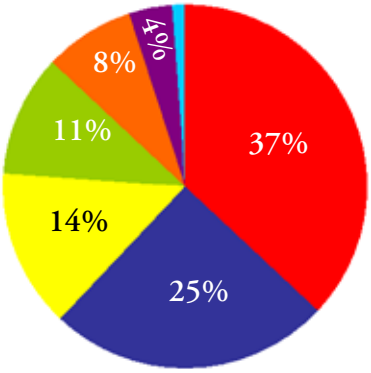
Because of the growing number of adults with CF, the CF Foundation has developed guidelines for the care of adults with CF. The CF Foundation also mandated the development of adult care programs, or clinics for adults with CF, and is providing grants to help more doctors train to care for adults with CF. Also, it is important to help teens transition from depending on their parents or another adult to taking charge or managing their own health. Your care center can help teach children and teens how to manage CF. The charts below show that many adults with CF are leading active lives.

Education



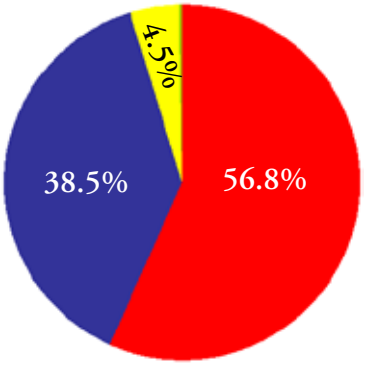
- Some College
- College Graduate
- High School Diploma
- Less Than High School

Employment



- Full-time
- Student
- Disabled
- Part-time
- Unemployed
- Homemaker
- Retired (1%)

Marital Status



- Single
- Married/Living Together
- Separated/Divorced
- Widowed (0.2%)

CF AND PREGNANCY

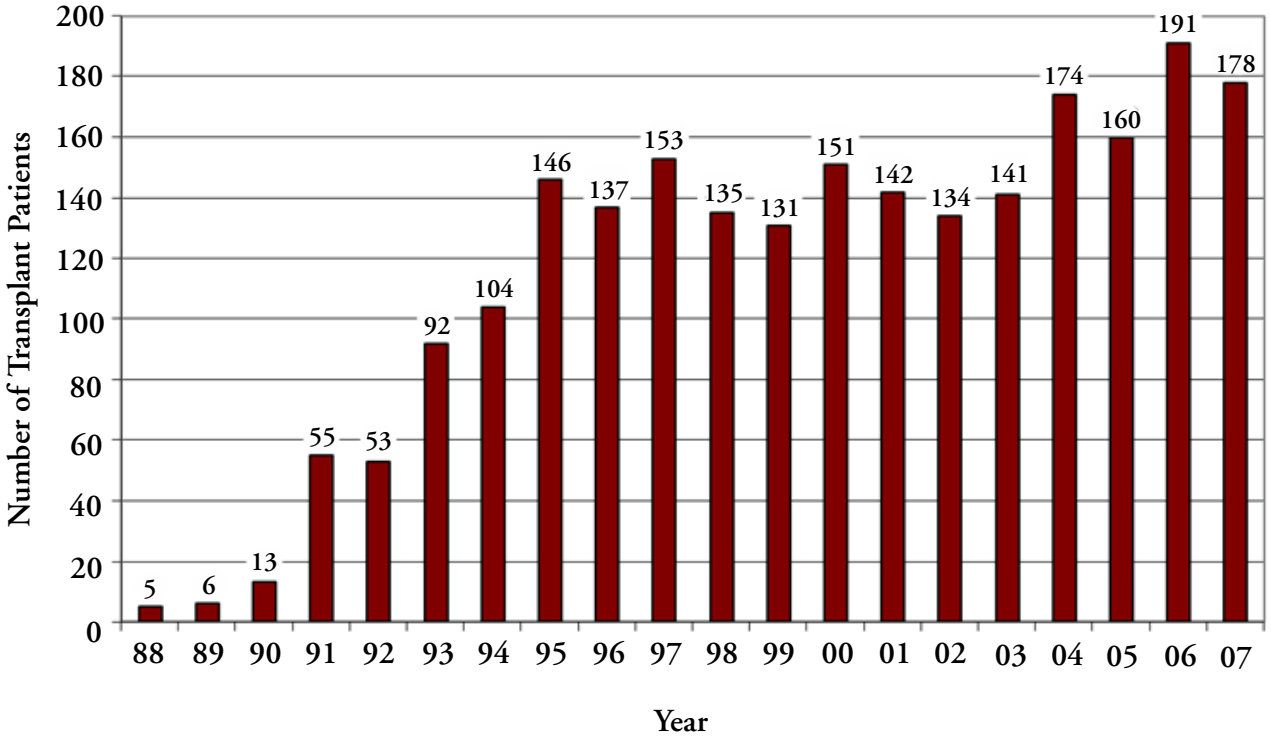
Many adults with CF wish to have children. In the 1980s, it was thought to be too risky for a woman with CF to get pregnant. Now, thanks to improvements in nutrition and lung function, many women with CF are able to have a healthy pregnancy and baby. In 2007, the Patient Registry reported that 239 women with CF were pregnant. Also, with advances in fertility medicine, more men with CF are able to father children than ever before. Ask your care center to learn what you should consider before starting a family. You can learn more about CF adult fertility by watching the Web cast on the CF Foundation's Web site (**www.cff.org**).

TRANSPLANTATION AND END-OF-LIFE CARE

Goal 7: Everyone with CF will be supported by their CF care center when making decisions about transplantation and end-of-life care.

People with CF who have severe lung disease often think about having a lung transplant. However, a lung transplant is risky and the supply of good donor lungs for transplant is limited. It is important to understand who can benefit from a lung transplant and when is the best time for a transplant. Research with data from the Patient Registry has been used to help identify who is most likely to benefit. The national process used to decide who is listed first to get donor lungs changed in 2005. The graph below shows that the change in that process did not decrease the number of lung transplants for people with CF. Of course, the ultimate goal of CF research and care is that no one with CF will need a lung transplant. To learn more about lung transplants and organ donation, visit the "Treatments" section of the CF Foundation's Web site at **www.cff.org**.

Number of People With CF Who Received Lung Transplants, 1988 to 2007



WHO ARE THE PATIENTS IN THE CF FOUNDATION'S PATIENT REGISTRY — A SUMMARY OF THE 2007 DATA.

CF patients (number)	24,511
Newly diagnosed patients in 2007 (number)	717
Patients diagnosed by NBS (%)	30.7
Age at diagnosis (median)	6 months
Age range	0 to 80 years
Total number of deaths	394
Predicted median survival	37.4 years
Patients 18 years and older (%)	45.4
Race/Ethnicity (%)	
Caucasian	94.3
Hispanic (black or white)	6.8
African American	4.2
Males (%)	52.0
Genotyped (%)	88.8
Home therapy (%)	
IV antibiotics	21.1
Oxygen	6.2
Supplemental feeding – tube	10.7
oral only	38.2
Clinical trial participation (number)	3,131
FEV_1 % predicted (mean)	75.9
Taking pancreatic enzyme supplements (%)	90.9
Median BMI percentile for patients 2-20 years* (%)	47.3
Median BMI for patients ≥ 21 years* (%)	21.7
Respiratory cultures positive for (%)	
P. aeruginosa	54.4
B. cepacia complex	2.9
S. aureus	51.4
S. maltophilia	12.6
MRSA	21.2
Complications (%)	
Diabetes (CFRD)/glucose intolerance	20.6
Bone disease (patients ≥ 18 years)	20.6
Liver disease	10.8
Nasal polyps requiring surgery	3.5
Transplants (numbers)	
Lung:	
Bilateral	174
Lobar-cadaveric	5
Lobar-living related donor	1
Liver:	12
Therapies**	
TOBI® (tobramycin)	66.5
Pulmozyme® (rhDNase)	74.0
Ibuprofen	4.6
Zithromax® (azithromycin)	63.3
Hypertonic Saline	34.2
Total pregnancies among women aged 13 to 45 (number)	239
Live births (per 100 women age 13 to 45)	2.0

*The Centers for Disease Control and Prevention have calculators for Body Mass Index (BMI). The national goal for children with CF ages 2-20 years is 50th BMI percentile. For adults with CF the national goal for weight is a BMI of 23 for males and 22 for females. For more information see **www.cdc.gov/nccdphp/dnpa/heatlhyweight/assessingbmi/index.htm**.

**This is the percentage of patients who are eligible for a therapy and had it prescribed at least once in 2007.

NUMBER OF PATIENTS BY STATE IN THE CF PATIENT REGISTRY

State	Number	Percent
Alabama	393	1.6
Alaska	60	0.24
Arizona	369	1.51
Arkansas	232	0.95
California	1,898	7.74
Colorado	484	1.97
Connecticut	301	1.23
Delaware	48	0.2
District of Columbia	20	0.08
Florida	1,134	4.63
Georgia	728	2.97
Hawaii	3	0.01
Idaho	157	0.64
Illinois	947	3.86
Indiana	570	2.33
Iowa	341	1.39
Kansas	282	1.15
Kentucky	465	1.9
Louisiana	288	1.17
Maine	198	0.81
Maryland	478	1.95
Massachusetts	779	3.18
Michigan	904	3.69
Minnesota	549	2.24
Mississippi	217	0.89
Missouri	636	2.59
Montana	108	0.44

State	Number	Percent
Nebraska	221	0.9
Nevada	150	0.61
New Hampshire	171	0.7
New Jersey	611	2.49
New Mexico	124	0.51
New York	1,564	6.38
North Carolina	776	3.17
North Dakota	67	0.27
Ohio	1,400	5.71
Oklahoma	258	1.05
Oregon	300	1.22
Pennsylvania	1,306	5.33
Puerto Rico	1	0
Rhode Island	79	0.32
South Carolina	340	1.39
South Dakota	95	0.39
Tennessee	518	2.11
Texas	1,364	5.56
Utah	315	1.29
Vermont	127	0.52
Virgin Islands	0	0.0
Virginia	682	2.78
Washington	540	2.2
West Virginia	205	0.84
Wisconsin	617	2.52
Wyoming	44	0.18
Foreign	46	0.19

SOURCE OF DATA:
Cystic fibrosis patients currently under care at CF Foundation-accredited care centers in the United States, 2007

SUGGESTED CITATION:
Cystic Fibrosis Foundation Patient Registry
2007 Annual Data Report
Bethesda, Maryland

Cystic Fibrosis Foundation

Adding *tomorrows* every day.

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