To the CF Community and Friends,

We are pleased to present the Cystic Fibrosis Foundation’s 2013 Patient Registry Annual Data Report.

For close to 50 years, the Foundation has collected information on the health of people with cystic fibrosis who receive care at Foundation-accredited care centers. We then share the information with the wider CF community, highlighting trends in key health outcomes to help people with CF and their families, clinicians and researchers work together to raise the quality of care.

Thanks to steady progress in CF care and treatment, the face of the disease has changed dramatically over the last few decades. We are now on the cusp of an important milestone, when more than half of those with CF in the United States will be 18 years and older, and we anticipate continued growth in the adult CF population in the years to come.

Positive trends shown in this year’s report include:

- Continued improvements in pulmonary function and nutritional status
- Increase in the number of new CF diagnoses through newborn screening
- Decrease in lung infections from Pseudomonas aeruginosa and MRSA

The data also show that much work remains in order for all people with CF to be better able to lead healthy and fulfilling lives. Many people with CF still require hospitalization for treatment of exacerbations and, as the CF population ages, many now face other health problems like CF-related diabetes and depression, which add to the daily demands of living with this disease. We remain committed to addressing these challenges.

This year, we have used more graphics to summarize the data and convey more fully the impact that CF has on those living with the disease. We hope this report encourages people with CF to partner with their care center teams and take an active role in shaping an individualized care plan to stay healthy and thrive.

We are deeply grateful to all who have contributed to this report, especially people with CF and their families who so generously agree to share their information.

Thank you for your continued commitment to our mission to cure CF.

Sincerely,

Preston W. Campbell, III, MD
Executive Vice President
Medical Affairs

Bruce C. Marshall, MD
Senior Vice President
Clinical Affairs

The Mission of the Cystic Fibrosis Foundation

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment, and ensuring access to high-quality, specialized care.
Highlights of CF Foundation Patient Registry Data

From the analysis of the CF Foundation Patient Registry data in 2013

More than 28,000 people with CF were seen at a CF Foundation-accredited care center and consented to have their data or their child’s data entered into the Registry. Almost 50 percent of those followed in the Registry were age 18 years or older.

The median predicted age of survival has increased from 33.4 years in 2003 to 40.7 years in 2013.

66% of new CF diagnoses were made in the first year of life.

Registry data shows continuous improvement in nutrition and pulmonary health outcomes in children and adults.

Pseudomonas prevalence is declining and the prevalence of MRSA has stabilized. Nontuberculous mycobacteria (NTM) infections are of concern.

"2,697 people with CF were 40 years or older.

Sweat testing is an extremely valuable diagnostic test, yet fewer people currently have a sweat test recorded in the Registry than in the past. This is especially common among those with two copies of the F508del mutation.

97% of people with CF have had their mutations identified through genetic testing.

Of adults with CF, 46% were working full time or part time and 22% were students.

About the CF Foundation Care Model

• Care Center Network
• CF Foundation Clinical Care Practice Guidelines
• Quality Improvement Initiative
• About the CF Foundation Patient Registry
• CF Foundation Resources and Assistance Programs

Overview of the Health of People with CF and the Standards of Care in the CF Foundation Care Center Network

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• Diagnosis of CF
• Sweat Test Data
• CF Genetics
• CF Clinical Care Practice Guidelines: Care, Screening and Prevention
• Microbiology
• Growth and Nutrition
• Lung Health
• Complications
• Transplantation
• Survival

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About the CF Foundation Care Model

Care Center Network

The CF Foundation accredits and funds a nationwide network of more than 120 care centers. Multidisciplinary teams of health care professionals at the care centers work together to provide expert, age-appropriate care tailored to meet the unique needs of individuals living with CF.

Each center undergoes an assessment by the CF Foundation’s Care Center Committee before it receives accreditation and funding. Accredited centers are reevaluated annually to ensure that people with CF receive effective and consistent levels of care and state-of-the-art treatments.

The CF Foundation’s care center network has been widely recognized as a national model for care of a chronic disease and for driving improvements in care.

The Multidisciplinary Team

<table>
<thead>
<tr>
<th>Required Team Members</th>
<th>Recommended Team Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>nurse</td>
<td>physical therapist</td>
</tr>
<tr>
<td>physician</td>
<td>research coordinator</td>
</tr>
<tr>
<td>respiratory therapist</td>
<td>psychologist</td>
</tr>
<tr>
<td>dietitian</td>
<td>pharmacist</td>
</tr>
<tr>
<td>social worker</td>
<td>physical therapist</td>
</tr>
<tr>
<td>program coordinator</td>
<td>research coordinator</td>
</tr>
</tbody>
</table>

CF Foundation Clinical Care Practice Guidelines

The CF Foundation provides accredited care centers with clinical care practice guidelines, which are updated regularly based on the latest research, care and treatments. The Foundation brings together committees of subject-matter experts, including physicians, nurses, respiratory therapists and dietitians, along with adults with CF and CF parents, to develop care recommendations on each topic.

Quality Improvement Initiative

Through its quality improvement initiative, the CF Foundation works closely with care centers to ensure all people with CF receive the highest quality of care. The quality improvement initiative is aimed at identifying best practices for CF care and treatment, and providing training and tools to implement improvements across the care center network. People with CF and their families are important partners in this process.

About the Cystic Fibrosis Foundation Patient Registry

Each year, information on the health status of children and adults with CF who receive care at CF Foundation-accredited care centers is entered into the Registry. This information provides critical data to help care teams and researchers identify new health trends, recognize the most effective treatments, design CF clinical trials and develop clinical care practice guidelines.

Uses of the Cystic Fibrosis Foundation Patient Registry

- **Disease Surveillance**
  - Track progress in curing CF and the impact of treatments
- **Framework for Clinical Trials**
  - Test promising new therapies
- **Post-Marketing Surveillance Studies**
  - Ensure safety and effectiveness of approved products
- **Quality Improvement**
  - Provide all patients with high-quality care
- **Comparative Effectiveness Research**
  - Promote evidence-based clinical decision making

CF Foundation Resources and Assistance Programs

The CF Foundation offers a variety of resources and programs to help people with CF obtain essential CF care and treatments. Please refer to the appendix in the back of this report for information on patient assistance resources.

In 2013, 25% of people with CF participated in a patient assistance program through CF or another source.
Overview of the Health of People with CF and the Standards of Care in the CF Foundation Care Center Network

Demographics

Records of 28,103 people with CF were included in the Registry in 2013. People with CF are living longer and healthier lives than ever before. Today, nearly half of all people with CF in the United States are adults. We project that survival will continue to improve over the next decade and beyond.

Number of People with CF Included in the Registry in Each State

Distribution of Race/Ethnicity among People with CF

Number of People with CF age 18 years or older

As people with CF are living longer and pursuing more opportunities, there are more college graduates in the CF population. There are also more adults who are working full time or part time. Since the late 1990s, the number of people with CF with college degrees has more than doubled.

Characteristics of Adults 18 Years and Older with CF in 2013

Education

Marital Status

Employment

Number of Children and Adults with CF, 1986–2013
Diagnosis of CF

Nationwide newborn screening for CF has been in place since 2010. As a result, more people with CF are now diagnosed in infancy, often before symptoms of the disease appear. While a growing proportion of people with CF are diagnosed by newborn screening, some are not diagnosed until adolescence or adulthood. Early diagnosis allows for earlier treatment, which may lead to better lung function and nutritional outcomes later in life.

While newborn screening provides opportunities for early intervention, it also increases the risk of misdiagnosing symptomless infants. In these cases, infants may receive unneeded CF treatments that can be potentially harmful. Visiting a CF Foundation-accredited care center to receive a complete diagnostic evaluation is extremely important for people who are newly diagnosed. A complete diagnostic evaluation includes a sweat test, genetic test and clinical evaluation.

Age at Diagnosis for all People with CF in the Registry, 2013

- Under 1 Year: 65.7%
- 1 Year Old: 6.6%
- 2-15 Years Old: 20.8%
- 16 Years and Older: 6.6%
- Prenatal: 2.3%
- Under 1 Month: 29.0%
- 1 to 3 Months: 13.2%
- 4 to 6 Months: 12.2%
- 7 to 11 Months: 9.0%

Sweat Test Data

The CF Foundation guidelines for diagnosis of cystic fibrosis recommend that a sweat chloride test be part of the diagnostic evaluation for CF. Despite this recommendation, there is a decrease in the number of individuals with a sweat chloride value reported in the Registry among individuals who are newly diagnosed and especially among those with two copies of the F508del mutation. This decrease in reported sweat tests may be due to an increased reliance on genetic testing to determine a definitive diagnosis of CF.

Percent of New Diagnoses Detected by Newborn Screening, 1990-2013

- 1990: 18%
- 1991: 20%
- 1992: 22%
- 1993: 24%
- 1994: 26%
- 1995: 28%
- 1996: 30%
- 1997: 32%
- 1998: 34%
- 1999: 36%
- 2000: 38%
- 2001: 40%
- 2002: 42%
- 2003: 44%
- 2004: 46%
- 2005: 48%
- 2006: 50%
- 2007: 52%
- 2008: 54%
- 2009: 56%
- 2010: 58%
- 2011: 60%
- 2012: 62%
- 2013: 64%

Percent of Patients with Sweat Chloride Values Reported by Year of Diagnosis, 1986-2013

- 1986: 80%
- 1987: 82%
- 1988: 85%
- 1989: 88%
- 1990: 90%
- 1991: 91%
- 1992: 92%
- 1993: 93%
- 1994: 94%
- 1995: 95%
- 1996: 96%
- 1997: 97%
- 1998: 98%
- 1999: 99%
- 2000: 100%
- 2001: 100%
- 2002: 100%
- 2003: 100%
- 2004: 100%
- 2005: 100%
- 2006: 100%
- 2007: 100%
- 2008: 100%
- 2009: 100%
- 2010: 100%
- 2011: 100%
- 2012: 100%
- 2013: 100%

Percent of Patients with Sweat Chloride Reported by Year of Diagnosis, 1988–2013

- 1988: 60%
- 1989: 70%
- 1990: 80%
- 1991: 90%
- 1992: 100%
- 1993: 97%
- 1994: 97%
- 1995: 97%
- 1996: 97%
- 1997: 97%
- 1998: 97%
- 1999: 97%
- 2000: 97%
- 2001: 97%
- 2002: 97%
- 2003: 97%
- 2004: 97%
- 2005: 97%
- 2006: 97%
- 2007: 97%
- 2008: 97%
- 2009: 97%
- 2010: 97%
- 2011: 97%
- 2012: 97%
- 2013: 97%

Percent of newly diagnosed people with CF with sweat values reported.

- 1993: 97%
- 2003: 82%
- 2013: 75%
CF Genetics

In people with CF, mutations in both copies of the cystic fibrosis transmembrane conductance regulator (CFTR) gene disrupt normal production of the CFTR protein. Different mutations cause CFTR to malfunction in different ways. In some people with CF, little to no CFTR is produced. In others, the defective protein is produced, but cannot move to the surface of the cell where it is needed to regulate the transfer of chloride and water in and out of cells. In others, CFTR is produced and moves to the surface of the cell, but the gate that controls chloride movement does not open properly. The malfunctioning CFTR leads to an accumulation of unusually thick and sticky mucus in the lungs, pancreas and other organs.

Today, as new therapies are developed to target problems caused by specific CF mutations, it is extremely important for each person with CF to know his or her mutations. There are more than 1,500 known CFTR mutations, many of which researchers have categorized into different groups. People with two mutations in classes I, II and III typically exhibit more severe pulmonary disease and pancreatic insufficiency as compared to people with at least one mutation in classes IV and V.

**CFTR Mutation Classes**

The chart below shows just one of the ways that researchers classify CFTR mutations. Individuals with CF can consult with a genetic counselor or other member of their care team to learn more about their specific mutations. To find more information on CFTR and mutation classes, visit www.cftr2.org.

<table>
<thead>
<tr>
<th>MUTATION</th>
<th>NUMBER OF PEOPLE</th>
<th>PERCENT OF PEOPLE WITH ONE OR MORE COPY OF THE MUTATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>F508del</td>
<td>23,478</td>
<td>86.4</td>
</tr>
<tr>
<td>G542X</td>
<td>1,252</td>
<td>4.4</td>
</tr>
<tr>
<td>G551D</td>
<td>1,182</td>
<td>4.4</td>
</tr>
<tr>
<td>R117H</td>
<td>767</td>
<td>2.8</td>
</tr>
<tr>
<td>N1303K</td>
<td>672</td>
<td>2.5</td>
</tr>
<tr>
<td>W1282X</td>
<td>625</td>
<td>2.3</td>
</tr>
<tr>
<td>R553X</td>
<td>493</td>
<td>1.8</td>
</tr>
<tr>
<td>G542X</td>
<td>1,252</td>
<td>4.4</td>
</tr>
<tr>
<td>R117H</td>
<td>767</td>
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<tr>
<td>W1282X</td>
<td>625</td>
<td>2.3</td>
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<tr>
<td>R553X</td>
<td>493</td>
<td>1.8</td>
</tr>
<tr>
<td>621+1G-&gt;T</td>
<td>437</td>
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</tr>
<tr>
<td>1717-1G-&gt;A</td>
<td>425</td>
<td>1.6</td>
</tr>
<tr>
<td>3849+1G-&gt;C</td>
<td>411</td>
<td>1.5</td>
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<td>2789+1G-&gt;A</td>
<td>369</td>
<td>1.4</td>
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<td>3120+1G-&gt;A</td>
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<td>1.0</td>
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<td>1.0</td>
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<tr>
<td>3507del</td>
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<td>0.8</td>
</tr>
<tr>
<td>D1152H</td>
<td>196</td>
<td>0.7</td>
</tr>
<tr>
<td>R1152X</td>
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</tr>
<tr>
<td>3A5delI</td>
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<td>0.7</td>
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<tr>
<td>G85E</td>
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<tr>
<td>R563T</td>
<td>165</td>
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</tr>
<tr>
<td>R347P</td>
<td>158</td>
<td>0.6</td>
</tr>
<tr>
<td>2184insA</td>
<td>151</td>
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</tr>
<tr>
<td>R334W</td>
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<tr>
<td>A455E</td>
<td>142</td>
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</tr>
<tr>
<td>Q493X</td>
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<td>0.5</td>
</tr>
<tr>
<td>2184delA</td>
<td>116</td>
<td>0.4</td>
</tr>
</tbody>
</table>

CF Clinical Care Practice Guidelines: Care, Screening and Prevention

CF clinical care practice guidelines are developed by expert multidisciplinary committees, based on published evidence and clinical experience. Guidelines are intended to inform care centers about CF care and treatment best practices and to be adapted by care center teams to the needs, preferences and values of the individual with CF and his or her family.

Current CF Foundation clinical care practice guidelines recommend that individuals ages 6 and older visit their care center at least four times, receive four microbiological cultures and perform two pulmonary function tests (PFTs) per year. There are other annual guidelines for CF care, some of which are listed below.

CF Foundation Annual Clinical Care Practice Guidelines

<table>
<thead>
<tr>
<th>Clinic Visits</th>
<th>Cultures</th>
<th>PFTs</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

The majority of people with CF followed in the Registry receive care as recommended by the Guidelines; however, adults with CF do not receive guideline-recommended care to the same extent as children. There are various possible reasons for this difference. Teens and adults may be busy with school or jobs, and some may have milder disease.

Care, Screening and Prevention Guidelines for People with CF

<table>
<thead>
<tr>
<th>ELIGIBILITY CRITERIA FOR RECOMMENDATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
</tr>
<tr>
<td>If 6 years of age or older</td>
</tr>
<tr>
<td>Physically able to perform the test</td>
</tr>
</tbody>
</table>

Prevalence of Respiratory Microorganisms, 1988–2013

Microbiology

Pulmonary infections are a serious and chronic problem for many living with CF. People with CF are at greater risk of getting lung infections because the thick and sticky mucus that accumulates in their lungs allows germs to thrive and multiply. The prevalence of the bacteria, Pseudomonas aeruginosa or Pseudomonas has been gradually decreasing over time in people with CF. Prevalence of nontuberculous mycobacteria (NTM) infections is increasing in the general population. This is of concern because people with CF are at a higher risk of developing NTM infections which require long periods of treatment with multiple antibiotics.

To help reduce the spread of germs, the infection prevention and control guidelines for CF were created. These CF Foundation guidelines provide recommendations for people with CF, their families and CF health care professionals to help reduce the spread of germs in the clinic and hospital setting, and at home, school or work.

Prevalence of Respiratory Microorganisms in People with CF, 1988–2013

Change in percent of people with CF with a positive culture of Pseudomonas over the last 10 years

Percent of people with CF tested between 2010 and 2013 who had NTM infections
Growth and Nutrition

Children and teens with CF need adequate nutrition to grow and prosper, and it’s important for adults to maintain proper nutrition to stay healthy. Because of the thick secretions that build up in the pancreas and prevent the release of digestive enzymes, people with CF have difficulty absorbing vital vitamins and nutrients from food, which leads to poor growth and malnutrition. To address this, most people with CF take pancreatic enzyme supplements.

In recent decades, nutritional outcomes have improved markedly for both children and adults. Body mass index (BMI) and BMI percentile are two important measures for assessing growth, nutrition and gastrointestinal function in people with CF.

Despite the gains in BMI, height and weight percentiles among people with CF remain below the 50th percentile, suggesting room for improvement.

Better nutrition is associated with better lung function in people with CF. This association suggests that maintaining a healthy weight is important not only to nutrition and growth, but to lung function as well. This association is especially important for infants whose length and weight can be measured, but who cannot perform lung function tests.

Median BMI Value by Age, In Adults 20 years and Older, 1988-2013

Median Nutritional Outcome Percentiles for Children and Adolescents Ages 2 to 19 years, 1986-2013

BMI Percentile
BMI percentile matches a child’s BMI to other children in the United States of the same age and gender. A BMI of the 50th percentile means half of the children of the same age and gender are larger and half are smaller.
Lung Health

Pulmonary function in individuals with CF has improved over time, but the pattern of decreasing pulmonary function beginning in adolescence persists.

Research shows that people with CF of all ages, including infants, have some lung damage — even when FEV1 percent predicted is within the normal range. This damage to the lungs is primarily the result of mucus buildup and lung infections.

To keep their lungs healthy, people with CF must take a number of drugs. Most pulmonary medications recommended by CF care providers are widely used by people with CF. However, medications alone cannot keep CF lungs healthy, and people with CF also use various airway clearance techniques (ACTs), including exercise, to help move mucus out of the lungs.

Despite notable improvements in pulmonary function and nutritional status over the past two decades, a significant proportion of people with CF in the Registry are still treated with IV antibiotics for pulmonary exacerbations.

Median FEV1 Percent Predicted for People with CF by Age, 1988-2013

FEV1 is a measure of lung function. It 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 in 1993 and 2013

Median FEV1 Percent Predicted in 18-Year-Olds, 1988-2013
Complications

CF is often associated with complications other than lung disease and impaired nutritional status. These complications can be a direct result of the disease or a result of treatments for CF.

Detecting complications early and managing them properly is crucial for the health and well-being of those with CF. Complications of CF include cystic fibrosis-related diabetes (CFRD), liver disease, bone disease, distal intestinal obstructive syndrome (DIOS), gastroesophageal reflux disease (GERD) and depression.

Prevalence of Common Complications by Age in 2013

A pulmonary exacerbation refers to a period of time when IV antibiotics are administered either during a hospitalization or via home IV therapy in response to worsening signs and symptoms of lung disease.
Complications

Cystic Fibrosis-Related Diabetes (CFRD)

CFRD is a form of diabetes that is unique to people with CF. People with CFRD have to undergo more treatments than those without the complication and most commonly use insulin. It is one of the most widespread complications of the disease, especially among adults with CF. As the number of adults with CF has increased, so has the prevalence of CFRD. CFRD is also more common in people with mutations in classes I – III.

Research shows that early diagnosis and treatment of CFRD leads to better nutrition and pulmonary function. The CF care guidelines for CFRD recommend that people with CF ages 10 and older should be tested annually for CFRD via the oral glucose tolerance test (OGTT).

Transplantation

Lung transplantation remains an option for some people with CF who have severe lung disease. However, lung transplantation has its own risks and requires life-long, post-transplant care.

The Registry also collects data on people with CF who have had other types of transplants, and there were 135 people with CF followed who received a kidney, heart or liver transplant in 2013 or in a prior year.

In 2013, 245 people with CF received a lung transplant. The median age of recipients was 31 years.

Number of Patients Receiving a Lung Transplant, 1990–2013
Survival

People with CF are living longer than ever before with the median predicted survival age continuing to increase.

**Median Predicted Survival Age, 1989–2013 (in 5 year bands)**

<table>
<thead>
<tr>
<th>Year</th>
<th>Median Predicted Survival Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1989–1993</td>
<td>24.7</td>
</tr>
<tr>
<td>1994–1998</td>
<td>28.0</td>
</tr>
<tr>
<td>1999–2003</td>
<td>32.4</td>
</tr>
<tr>
<td>2004–2008</td>
<td>36.7</td>
</tr>
<tr>
<td>2009–2013</td>
<td>40.7</td>
</tr>
</tbody>
</table>

The median predicted survival age is the age to which half of the current Registry population would be expected to survive, given their ages in 2013 and assuming that mortality rates do not change. Median predicted survival age is calculated using a method called life table analysis.

The CF Foundation is committed to promoting individualized treatment and ensuring access to high-quality, specialized care for people with CF. The findings from 2013 Registry data provide much insight into the current health of the CF population and also provide clinicians with a road map for improving care. As new treatments and therapies emerge, the Registry will remain a rich resource for researchers, clinicians, people with CF and families as they partner to improve care, treatment and research.

**Appendix of Resources**

**About the CF Foundation Care Model**

- **Care Center Network**
  - CF Foundation Treatment and Care Center Network
    - www.cff.org/treatments/CareCenterNetwork/
  
- **Partnering for Care: CF Experts Talk About Managing Life with CF**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/PartneringCare

**CF Foundation Clinical Care Practice Guidelines**

- **CF Care Guidelines**
  - The CF Foundation offers guidelines to help care teams improve the care they provide to people with CF.
    - www.cff.org/treatments/CFCareGuidelines

**Quality Improvement Initiative**

- **Improve Your CF Care**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/QualityImprovement/ImproveYourCFCare/

**Overview of the Health of People with CF and the Standards of Care in the CF Foundation Care Center Network**

- **Demographics**
  - CF Healthcare Coverage and Advocacy
    - www.cff.org/treatments/CFCareGuidelines/Demographics

- **CF Care Guidelines – Infection Prevention and Control**
  - CF Infants Care: First Year of Life
    - www.cff.org/treatments/CFCareGuidelines/InfectionControl

- **Get Germ Smart**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/GermSmart/

- **Information about Burkholderia cepacia**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/Bcepacia

- **Information about Allergic Bronchopulmonary Aspergillosis**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/ABPA/

- **Methicillin-resistant Staphylococcus aureus (MRSA) and Cystic Fibrosis**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/MRSA/mRSA/

- **Webcasts on Germs and Infection Control**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/Germs

**Sweat Test Data**

- **The Sweat Test**
  - CF Foundation
    - www.cff.org/aboutCF/testing/sweattest/

**CF Genetics**

- **About CF Genetics**
  - CF Foundation
    - www.cff.org/aboutCF/testing/Genetics

- **CF Mutation Analysis Program**
  - CF Foundation
    - www.cff.org/LivingWithCF/AssistanceResources/MAP

**Microbiology**

- **Additional Clinical Initiatives: Burkholderia cepacia, Methicillin-resistant Staphylococcus aureus (MRSA) and Nontuberculous Mycobacteria (NTM)**
  - CF Foundation
    - www.cff.org/LivingWithCF/AssistanceResources/AdditionalClinicalInitiatives

- **Centers for Disease Control and Prevention (CDC)**
  - Information on Handwashing
    - www.cdc.gov/handwashing

- **Centers for Disease Control and Prevention (CDC)**
  - Information on Vaccines
    - www.cdc.gov/vaccines

- **CF Care Guidelines – Age Specific Care**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/AgeSpecificCare

- **CF Infant Care: First Year of Life**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/CInfantCare

- **Testing for Cystic Fibrosis**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/Testing

- **Webcast – CF Infant Care: First Year of Life**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/AgeSpecific/CInfant_Care

- **About CF Genetics**
  - CF Foundation
    - www.cff.org/aboutCF/testing/Genetics

- **CF Mutation Analysis Program**
  - CF Foundation
    - www.cff.org/LivingWithCF/AssistanceResources/MAP

- **Clinical and Functional Translation of CFTR (CFTR2)**
  - CF Foundation
    - www.cff.org/Research/DrugDevelopmentPipeline/AdditionalClinicalInitiatives

- **Centers for Disease Control and Prevention (CDC)**
  - Information on Handwashing
    - www.cdc.gov/handwashing

- **Centers for Disease Control and Prevention (CDC)**
  - Information on Vaccines
    - www.cdc.gov/vaccines

- **CF Care Guidelines – Infection Prevention and Control**
  - CF Foundation Webcasts
    - www.cff.org/treatments/CFCareGuidelines/InfectionControl

- **Get Germ Smart**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/GermSmart/

- **Information about Burkholderia cepacia**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/Bcepacia

- **Information about Allergic Bronchopulmonary Aspergillosis**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/ABPA/

- **Methicillin-resistant Staphylococcus aureus (MRSA) and Cystic Fibrosis**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/StayingHealthy/MRSA/MRSA/

- **Webcasts on Germs and Infection Control**
  - CF Foundation Webcasts
    - www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/Germs