Body Mass Index (BMI) reflects weight relative to height. In children, BMI is captured as a percentile because height fluctuates as children grow.

This snapshot of 2019 Patient Registry data shows general trends for people ages 12-44. To understand more about your individual health, ask your care team for your Patient Summary Report. For more information on other age groups, visit cff.org/PatientRegistry.

**Ages 12-17**
4,769 People

- **93%** Median FEV1 Percent Predicted
- **57%** BMI Percentile

**Lung Transplants Reported in 2019**
15
which means
1 out of 318 patients received new lungs

**Ages 18-29**
8,237 People

- **78%** Median FEV1 Percent Predicted
- **23** BMI

**Lung Transplants Reported in 2019**
97
which means
1 out of 85 patients received new lungs

**Ages 30-44**
5,158 People

- **65%** Median FEV1 Percent Predicted
- **24** BMI

**Lung Transplants Reported in 2019**
94
which means
1 out of 55 patients received new lungs

*Body Mass Index (BMI) reflects weight relative to height. In children, BMI is captured as a percentile because height fluctuates as children grow.
REPORTED BEING HOSPITALIZED AT LEAST ONCE IN 2019

43%

38%

34%

AVERAGE LIFE EXPECTANCY

People with CF who are healthier tend to live longer. As they get older, they are expected to continue living longer. This is why average life expectancy increases among people in older age groups.

AGES 12-17
4,769 PEOPLE

46 YEARS

AGES 18-29
8,237 PEOPLE

49 YEARS

AGES 30-44
5,158 people

59 YEARS

These numbers do not account for potential benefits of CFTR modulators or improvements in care — and, most important, they do not predict how long any one person will live because they do not account for individual characteristics like behavior, mutations, or response to treatments.
As people with CF live longer, they can develop infections and complications. The following are among the most commonly-reported.

### Infections

<table>
<thead>
<tr>
<th>Microorganism</th>
<th>Ages 12-17</th>
<th>Ages 18-29</th>
<th>Ages 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspergillus</td>
<td>13%</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Achromobacter</td>
<td>5%</td>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>Nontuberculous mycobacteria</td>
<td>6%</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>B. cepacia</td>
<td>2%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>(Burkholderia cepacia complex)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRSA</td>
<td>29%</td>
<td>32%</td>
<td>25%</td>
</tr>
<tr>
<td>(Methicillin-resistant Staphylococcus aureus)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pseudomonas aeruginosa</td>
<td>35%</td>
<td>53%</td>
<td>68%</td>
</tr>
</tbody>
</table>

### Complications

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Ages 12-17</th>
<th>Ages 18-29</th>
<th>Ages 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sinus disease</td>
<td>32%</td>
<td>53%</td>
<td>61%</td>
</tr>
<tr>
<td>CF-related diabetes</td>
<td>13%</td>
<td>27%</td>
<td>36%</td>
</tr>
<tr>
<td>Depression</td>
<td>10%</td>
<td>27%</td>
<td>30%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>12%</td>
<td>23%</td>
<td>26%</td>
</tr>
<tr>
<td>ABPA</td>
<td>5%</td>
<td>9%</td>
<td>7%</td>
</tr>
</tbody>
</table>

(Allergic bronchopulmonary aspergillosis)
Living longer also means reaching more life milestones. The Registry captures the following, which indicate key milestones that people with CF and their families are now planning for. The following includes people reported in the Registry who have had a lung transplant.

**EDUCATION**
- 33.7% Some college
- 26% High school diploma
- 11% College graduate
- 17.8% Less than high school
- 2.6% Master’s/doctoral

**EMPLOYMENT**
- 51% Full-time
- 20% Unemployed
- 14% Retired
- 6% Homemaker
- 5.2% Part-time
- 1.6% Student
- 1.5% Unknown
- 12% Unemployed
- 9% Student
- 32% Full-time
- 2% Homemaker
- 2% Unknown
- 11.5% Disabled

**RELATIONSHIPS**
- 74% Single
- 21% Married/living together
- 4% Separated/divorced
- 1% Unknown

**AGES 18-29**
- 8.9% High school diploma
- 14% College graduate
- 20% Some college
- 16% Master’s/doctoral
- 14% Less than high school

**AGES 30-44**
- 36% College graduate
- 20% High school diploma
- 16% Master’s/doctoral
- 14% Some college
- 12% Less than high school

Cystic Fibrosis Foundation Patient Registry
2019 Patient Registry Snapshot
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