2019 PATIENT REGISTRY SNAPSHOT

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.

<table>
<thead>
<tr>
<th>AGES 12-17</th>
<th>AGES 18-29</th>
<th>AGES 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>4,769 PEOPLE</td>
<td>8,237 PEOPLE</td>
<td>5,158 PEOPLE</td>
</tr>
</tbody>
</table>

BMI

<table>
<thead>
<tr>
<th>AGES 12-17</th>
<th>AGES 18-29</th>
<th>AGES 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>93% MEDIAN FEV₁ PERCENT PREDICTED</td>
<td>78% MEDIAN FEV₁ PERCENT PREDICTED</td>
<td>65% MEDIAN FEV₁ PERCENT PREDICTED</td>
</tr>
</tbody>
</table>

BMI PERCENTILE

<table>
<thead>
<tr>
<th>AGES 12-17</th>
<th>AGES 18-29</th>
<th>AGES 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>57%</td>
<td>23 BMI</td>
<td>24 BMI</td>
</tr>
</tbody>
</table>

LUNG TRANSPLANTS

<table>
<thead>
<tr>
<th>AGES 12-17</th>
<th>AGES 18-29</th>
<th>AGES 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 LUNG TRANSPLANTS REPORTED IN 2019</td>
<td>97 LUNG TRANSPLANTS REPORTED IN 2019</td>
<td>94 LUNG TRANSPLANTS REPORTED IN 2019</td>
</tr>
</tbody>
</table>

which means

<table>
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<tr>
<th>AGES 12-17</th>
<th>AGES 18-29</th>
<th>AGES 30-44</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 OUT OF 318 PATIENTS RECEIVED NEW LUNGS</td>
<td>1 OUT OF 85 PATIENTS RECEIVED NEW LUNGS</td>
<td>1 OUT OF 55 PATIENTS RECEIVED NEW LUNGS</td>
</tr>
</tbody>
</table>

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

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

**Aspergillus**
- Ages 12-17: 13%
- Ages 18-29: 17%
- Ages 30-44: 17%

**Achromobacter**
- Ages 12-17: 5%
- Ages 18-29: 9%
- Ages 30-44: 8%

**Nontuberculous Mycobacteria**
- Ages 12-17: 6%
- Ages 18-29: 11%
- Ages 30-44: 10%

**B. cepacia**
- Ages 12-17: 2%
- Ages 18-29: 4%
- Ages 30-44: 4%

**MRSA**
- Ages 12-17: 29%
- Ages 18-29: 32%
- Ages 30-44: 25%

**Pseudomonas aeruginosa**
- Ages 12-17: 3%
- Ages 18-29: 8%
- Ages 30-44: 18%

### COMPLICATIONS

**Sinus Disease**
- Ages 12-17: 32%
- Ages 18-29: 53%
- Ages 30-44: 61%

**CF-Related Diabetes**
- Ages 12-17: 13%
- Ages 18-29: 27%
- Ages 30-44: 36%

**Depression**
- Ages 12-17: 10%
- Ages 18-29: 27%
- Ages 30-44: 30%

**Anxiety**
- Ages 12-17: 12%
- Ages 18-29: 23%
- Ages 30-44: 26%

**ABPA**
- Ages 12-17: 5%
- Ages 18-29: 9%
- Ages 30-44: 7%

**Note:** The above percentages reflect the prevalence rates for each condition across different age groups.
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
- 17.8% COLLEGE GRADUATE
- 26% HIGH SCHOOL DIPLOMA
- 11% LESS THAN HIGH SCHOOL
- 8.9% MASTER'S/DOCTORAL
- 2.6% UNKNOWN

**EMPLOYMENT**
- 32% FULL-TIME
- 9% UNEMPLOYED
- 12% HOMEMAKER
- 1.5% STUDENT
- 1.6% RETIRED
- 0.2% DISABLED
- 2% UNKNOWN

**RELATIONSHIPS**
- 74% SINGLE
- 21% MARRIED/LIVING TOGETHER
- 4% SEPARATED/DIVORCED
- 1% UNKNOWN

**AGES 18-29**
- 32% COLLEGE GRADUATE
- 14% HIGH SCHOOL DIPLOMA
- 20% SOME COLLEGE
- 16% MASTER'S/DOCTORAL
- 12% LESS THAN HIGH SCHOOL
- 2% UNKNOWN

**AGES 30-44**
- 51% FULL-TIME
- 14% PART-TIME
- 6% HOMEMAKER
- 5.2% UNEMPLOYED
- 2% STUDENT
- 0.2% RETIRED
- 2% DISABLED
- 6% UNKNOWN