Opportunities for CF Care Team Members and Researchers to Advocate

One conversation can make all the difference

In 2017, the U.S. Senate was considering the Better Care Reconciliation Act (BCRA), a bill that would have made accessing adequate, affordable care more difficult for people with cystic fibrosis. In the days before the vote, a woman in Maine approached Sen. Susan Collins at a Fourth of July parade. During their conversation, she told Sen. Collins about her grandson, who has CF, and her fears that he wouldn’t be able to get the care he needs to stay healthy if the bill were to pass. When the vote came to the floor, Sen. Collins voted “no,” — one of the deciding votes that defeated the bill — and cited that conversation as a major influence in her decision.

Your voice matters. One conversation can make all the difference.

Federal and state governments play a critical role in cystic fibrosis research, drug development, and the ability of people with cystic fibrosis to access the care and therapies they need. You have the power to inspire action and help shape public policy. Learn how you can help make a difference.

The Cystic Fibrosis Foundation engages with Medicaid officials, legislators, regulators, and public and private payers on the complexities of living with cystic fibrosis, and the innovative CF care model. This engagement ensures that any law put into place (1) helps people with CF access adequate, affordable care they need to stay healthy; and (2) supports research and development essential for identifying breakthrough treatments, and ultimately a cure for cystic fibrosis.

Every day, the CF Foundation advocates for:

- Adequate, affordable health insurance
- Robust funding for the U.S. Food and Drug Administration and the National Institutes of Health to support new breakthrough therapies in CF

Because of your unique insights about cystic fibrosis and CF care, your voice has the power to inspire action and help shape public policy.
Get Involved in CF Advocacy!

CF care teams and researchers have unique experiences and expertise that translate to effective CF advocacy. You understand firsthand why people with cystic fibrosis need affordable access to high-quality comprehensive care.

The Cystic Fibrosis Foundation relies on CF care teams and researchers, people with cystic fibrosis, and their families to raise awareness and promote policies that support access to specialized CF care and treatments. To be advocates, all CF care teams and researchers need is a passion for helping people with cystic fibrosis and the willingness to make their voices heard. Here are some ways CF care clinicians and researchers can get involved:

1. SIGN UP FOR ADVOCACY ALERTS
   Text FIGHTCF2019 to 52886 to join our advocacy network and help to shape the policies that improve access to high-quality specialized care.

2. TALK TO YOUR PATIENTS ABOUT ADVOCATING
   Encourage your patients to get involved with policy and advocacy by connecting them with their local CF Foundation chapter or sending them to www.cff.org/advocate to learn more.

3. INFORM PUBLIC AND PRIVATE PAYERS
   The CF Foundation engages with state Medicaid officials, private and public payers, and regulators to explain coverage challenges, barriers to access, and the innovative CF care model. Clinical expertise is powerful in educating decision-makers on how best to design programs and policies that create a positive coverage environment for people with CF.

4. HOST A CARE CENTER TOUR
   Inviting policy and decision-makers to tour a CF care center is a great way to educate them about CF and the complex care and treatments people with CF need to stay healthy. The CF Foundation can help plan and execute these tours.

5. ATTEND A CF FOUNDATION ADVOCACY EVENT
   Every year, the Foundation holds several advocacy events that enable advocates to meet face-to-face with representatives to talk about the needs of people affected by CF. Care teams and researchers are a powerful voice at these events — your experience provides invaluable insight into the complexities of living with cystic fibrosis, coverage challenges, and the innovative CF care model, and helps policymakers better understand this complex disease.

To alert the Cystic Fibrosis Foundation about an issue in your state, email publicpolicy@cff.org.