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 CF. 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 on her decision.

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

Federal and state governments play a vital 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 Foundation engages with Medicaid officials, legislators, regulators, and public and private payers on the complexities of living with CF, 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 CF.

Every day, the CF Foundation advocates for:

• Adequate, affordable, available health insurance for people with CF
• 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 CF and CF care, your voice has the power to inspire action and help shape public policy.

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#CFadvocacy
Get Involved in CF Advocacy!

CF care teams and researchers are well positioned to be CF advocates. There are several ways to advocate for federal and state policies that ensure people with CF have access to affordable and adequate health insurance for the highly-specialized care they require.

The CF Foundation relies on CF care teams and researchers, people with CF, 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 CF and the willingness to make their voices heard. Here are some ways CF care clinicians can get involved:

1. SIGN UP FOR ADVOCACY ALERTS
   By texting FIGHTCF to 52886, CF care teams and researchers will receive periodic communication about upcoming legislation, how to contact policymakers, and how they can get involved.

2. ATTEND A CF FOUNDATION ADVOCACY EVENT
   Every year, the CF Foundation holds several advocacy events like March on the Hill and Teen Advocacy Day in Washington, D.C., and State Advocacy Days at several state capitols, that help advocates from across the country meet face-to-face with their representatives and talk about the needs of the CF community. CF care teams and researchers have powerful voices at these events – their experience provides invaluable insight into the complexities of living with CF, coverage challenges, and the innovative CF care model and helps their policymakers better understand this complex disease.

3. WRITE AN OP-ED OR LETTER TO THE EDITOR
   An opinion editorial (op-ed) is a short opinion piece published in a local newspaper written by members of the community. The opinion section is one of the most widely read sections of the newspaper, so this is a great way to influence both the community and elected representatives.

4. 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.

5. 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.

To get involved in any of these efforts, email publicpolicy@cff.org.