RESPONDING TO THE NEEDS OF OUR COMMUNITY

The Cystic Fibrosis Foundation has been actively engaging state and federal policy makers throughout the COVID-19 pandemic to ensure that people with CF have continued access to care and coverage. While the Foundation responds to the changing needs of our community during the ongoing pandemic, we remain more committed than ever to our core goals: raising awareness of the disease, supporting policies that advance drug discovery and development, and advocating for access to adequate, affordable healthcare for all people with CF.

Federal Policy Initiatives

**Paid Leave:** The CF Foundation rallied more than 160 organizations to deliver a letter to Congress calling on it to expand paid leave for vulnerable populations like those with CF and their working household members for the duration of the pandemic.

**Out-of-State Licensing Requirements:** The CF Foundation supports the Temporary Reciprocity to Ensure Access to Treatment (TREAT) Act, which would enable temporary licensing reciprocity for the duration of the COVID-19 public health emergency and future national emergencies. This would ensure greater uniformity and remove barriers for providers who care for patients residing in other states.

**Expanded Access to Health Care:** Since the beginning of the pandemic, the CF Foundation has been a leader in pressing Congress to broaden access to health care while COVID-19 continues to be a threat. We have advocated for increasing the federal Medicaid match, creating a special enrollment period, and subsidizing COBRA for those who have lost their job during the pandemic.

**Vaccine Allocation:** The CF Foundation submitted comments on COVID-19 vaccine allocation to the Centers for Disease Control and Prevention’s Advisory Committee on Immunization Practices (ACIP). We called on the committee to ensure any COVID-19 vaccine allocation framework prioritizes high-risk populations for early access, clear communication to the public on the risks and benefits of different COVID-19 vaccines, transparency of pre-clinical and clinical trial data to help inform clinicians and patients, and affordability of COVID-19 vaccines for all.
State Policy Initiatives

COVID-19 Triage Plans: Many states and hospitals have developed ‘crisis standards of care’ or ‘triage’ plans, meant to help guide institutions and providers when making decisions about how to prioritize scarce medical resources. We have been working to educate policymakers and clinicians about how CF has changed and engaging with states to ensure people with CF have equal access to COVID-19-related care and treatment.

Telehealth Policies: Many states issued temporary flexibilities that expand access to telehealth services. We have been engaging with state Medicaid programs asking that they extend certain telehealth policies for as long as COVID-19 remains a threat so that people with CF can access their care without having to risk exposure to the virus. We are also speaking with patients and providers to get feedback on their experiences with telehealth services.

School Reopening: We sent letters to all state superintendents urging them to implement a remote learning option for the upcoming academic year to help safeguard students with CF and their families from exposure to COVID-19. Overall, we have received a positive response to our outreach, with most states offering some form of remote learning.

State Budgets and CF Programs: As a result of the COVID-19 pandemic, many states are facing budget constraints due to a variety of factors including decreased revenue and increased enrollment in public programs like Medicaid. As states form budgets for the upcoming year, our team is working to protect funding for Medicaid and essential state CF programs so that people with CF can continue to access their care.

Cystic Fibrosis Foundation COMPASS

Throughout the course of the pandemic, Compass team has supported the community by helping to connect callers with resources and information to address five major areas of need. These include:

1. Connecting people with legal experts to address work-related questions (e.g., job loss, FMLA, and sick leave.)

2. Identifying financial assistance for those experiencing financial hardship (e.g., living expenses including food, utilities, rent/mortgage and insurance premiums)

3. Navigating insurance challenges and comparing plan options due to pandemic-related financial hardships such as job loss or loss of income

4. Navigating access to care (e.g., telehealth, home spirometers)

5. Helping with school accommodations and legal protections related to returning to school

Cystic Fibrosis Foundation Compass is a personalized, one-on-one service that provides people living with cystic fibrosis, their families, and their care teams with a partner in dealing with challenges related to life with CF. The Compass team strives to provide excellent service to anyone living with CF or their loved ones, regardless of income or insurance status. We listen closely, explain thoroughly, and work through issues from start to finish.

Please contact us at 844-COMPASS (844-266-7277)

Hours of operation: Monday through Friday, 9 a.m. until 7 p.m. ET

Resources

- For more information on the impact of COVID-19 on our community, please check out our poster: COVID-19: The Socioeconomic Impact on the CF Community
- Clinicians: sign up to receive action alerts from the CF Foundation when your voice is needed most
- Also check out our statements, letters, and regulatory comments page on cff.org