RESPONDING TO OUR COMMUNITY’S NEEDS

The Cystic Fibrosis Foundation has been actively engaging state and federal policymakers 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 cystic fibrosis.

Federal Policy Initiatives

Paid Leave: The CF Foundation is leading the charge to expand paid family and medical leave to protect vulnerable populations like those living with CF and their working household members. To date, we’ve spurred community action through constituent messages to Congress, held a virtual congressional briefing, and sent letters to President-Elect Biden’s transition team and Congressional leadership outlining the necessity of expanded paid family and medical leave.

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: As public health authorities discuss the approval and distribution of COVID-19 vaccines, we continue to focus on educating state and federal decision-makers about the complexities of CF and why people with cystic fibrosis should receive priority access to COVID-19 vaccines along with others who are at increased risk of serious illness from COVID-19 infection. Please visit our COVID-19 Q&As page on cff.org for more information on what CFF is doing to support the community related to COVID-19 vaccines.
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 cystic fibrosis 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 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 2020-2021 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, the Foundation is working to protect funding for Medicaid and essential state CF programs so people with CF can continue to access their care.

Throughout the pandemic, Compass has supported the community by helping to connect individuals and families 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

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. Compass is available to any individual with CF, their family, or their care team, 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) or compass@cff.org.

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.