



February 1, 2021

Dr. Courtney N. Phillips
Secretary
Louisiana Department of Health

Dear Secretary Phillips:

On behalf of the approximately 350 people living with cystic fibrosis in Louisiana, we write today to urge the state to ensure people with high-risk medical conditions—including cystic fibrosis—are prioritized for early access to COVID-19 vaccines. We recognize the monumentally difficult task public health officials face when creating allocation plans that are both equitable and actionable during this crisis, and we appreciate the immense effort state public health departments have put into creating plans to allocate limited supplies of COVID-19 vaccines. However, we are deeply concerned that the state's vaccine plan would deny people with CF and others with high-risk medical conditions the ability to receive early COVID-19 vaccine access, despite guidance from the CDC.¹

Our comments below urge the state to immediately revise its vaccine prioritization plan to ensure those with CF and other high-risk medical conditions are prioritized for access to COVID-19 vaccines in accordance with the CDC's recommendations.

Background on Cystic Fibrosis and COVID-19

The Cystic Fibrosis Foundation is a national organization actively engaged in the research and development of new therapies for cystic fibrosis – a rare, life-threatening genetic disease that affects more than 30,000 people in the United States. The buildup of thick, sticky mucus in the lungs characteristic of the disease makes people with CF particularly prone to chronic respiratory infections. These chronic infections are punctuated by pulmonary exacerbations, events that are a risk factor for an irreversible decline of lung function and associated with morbidity and mortality. A significant proportion of pulmonary exacerbations are triggered by respiratory viral infections. With continued progress of the disease, some individuals with CF and advanced lung disease pursue lung transplantation.

The absent or malfunctioning protein that causes CF is also associated with a wide range of disease manifestations beyond the lungs, including pancreatic insufficiency that can lead to malnutrition, gastrointestinal issues, biliary cirrhosis, and diabetes mellitus.

While we have seen incredible progress in recent decades for those living with cystic fibrosis, COVID-19 represents a serious threat for this population. The strongest evidence to date on the threat COVID-19

¹ <https://ldh.la.gov/covidvaccine/>

poses to those with CF comes from a global analysis of 181 COVID-19 cases among people with CF.² From that analysis, it appears CF patients with advanced lung disease, those that are post-lung transplantation, and those with diabetes mellitus may be at risk of severe outcomes including death.

Due to the known risks posed by viral infections and multi-system manifestations of the disease described above, people with CF should be considered at increased risk of poor outcomes from COVID-19 infection and the Centers for Disease Control and Prevention (CDC) has listed CF as a condition that may put individuals at increased risk for worse outcomes.³

Individuals with Cystic Fibrosis Must Be Prioritized for Access to COVID-19 Vaccines

We are concerned that Louisiana’s vaccine allocation plan fails to account for the needs of high-risk patient populations, like those with CF, whose condition puts them at increased risk of severe illness and death from COVID-19 infection. We urge Louisiana to follow the allocation recommendations put forth by the CDC’s Advisory Committee on Immunization Practices (ACIP) and to heed further CDC guidance on the limitations of evidence for rare disease patients and the need for physician discretion in identifying individuals for early vaccine access.

The recommendations released by the ACIP are the result of months of careful deliberation by vaccine and public health experts and input from thousands of stakeholders. The ACIP and other decisionmakers sought to balance competing ethical principles and public health priorities, as well as the urgency of improving health equity in vaccine distribution plans. Importantly, the committee’s process has included meaningful public engagement and transparency on how the committee weighed different considerations related to prioritized populations. In its recommendations for allocation of currently available COVID-19 vaccines, the ACIP recommends vaccinating individuals with high-risk medical conditions in phase 1c.

The ACIP recommendations are accompanied by important CDC guidance on the limitations of available evidence on COVID-19’s impact for many disease groups, including rare diseases like CF.⁴ This CDC guidance recommends using clinical judgement in identifying patients whose individual risks factors warrant priority vaccine access but whose condition may not be on the CDC’s list of high-risk conditions.⁵ Together, these recommendations support prioritized vaccine access for people with CF and other rare disease populations that, due to small population size, are unable to generate the same level of evidence on the risk of severe illness from COVID-19 as substantially larger disease populations.

We urge Louisiana to revise the state’s COVID-19 vaccine prioritization plan by incorporating ACIP and CDC prioritization recommendations on individuals with high-risk conditions like those with CF. We further ask Louisiana to ensure clinician discretion may be used in identifying additional individuals at high-risk for prioritization purposes.

² Cosgriff, Rebecca et al. “The global impact of SARS-CoV-2 in 181 people with cystic fibrosis.” *Journal of Cystic Fibrosis* (2020), in press

³ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

⁴ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

⁵ <https://www.cdc.gov/vaccines/covid-19/phased-implementation.html>

Once again, we thank you for your attention and consideration of people with CF as you tackle these difficult issues. We look forward to working with you as the state continues to revise and develop further allocation recommendations for COVID-19 vaccines.

Sincerely,

A handwritten signature in black ink, appearing to read "Mary B. Dwight". The signature is fluid and cursive, with the first name "Mary" being the most prominent.

Mary B. Dwight

Chief Policy and Advocacy Officer
Senior Vice President of Policy and Advocacy
Cystic Fibrosis Foundation