February 1, 2021

Lori Shbinette
Commissioner
New Hampshire Department of Health and Human Services
129 Pleasant Street
Concord, NH 03301

Dear Commissioner Shbinette:

On behalf of the approximately 210 people living with cystic fibrosis in New Hampshire, 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.

We thank New Hampshire for incorporating important guidance in the state’s vaccine distribution plan from the Centers of Disease Control and Prevention (CDC) on the limitations of available evidence for rare disease populations and for allowing the use of clinical judgement in identifying patients whose individual risks factors warrant priority vaccine access.¹ However, we are deeply concerned that the state’s vaccine plans would deny some people with CF the ability to access COVID-19 vaccines alongside others with high-risk conditions due to criteria related to multiple comorbid conditions.²

Our comments below urge the state to immediately revise its vaccine prioritization plan to ensure those with CF are prioritized for access to COVID-19 vaccines with others with high-risk conditions in phase 1b of the state’s plan.

**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.

¹ https://www.cdc.gov/vaccines/covid-19/phased-implementation.html
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 poses to those with CF comes from a global analysis of 181 COVID-19 cases among people with CF.\(^3\) 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.\(^4\)

**Individuals with One High-Risk Condition Should be Prioritized for Access to COVID-19 Vaccines**

We urge New Hampshire to give equal priority to anyone with a condition that puts them at high-risk for severe disease from COVID-19 instead of prioritizing those with two or more comorbid conditions. We recognize the need for sub-group prioritization due to limited vaccine supplies. However, a focus on multiple conditions neglects other indications of disease severity or vulnerability. For instance, someone with cystic fibrosis who received a double lung transplant is especially vulnerable to complications from COVID-19, as they are taking medication to suppress their immune system. Those with advanced disease or CF-related diabetes may also be particularly vulnerable. Under an allocation scheme prioritizing those with two or more high-risk comorbid conditions according to the CDC, such individuals would receive a vaccine after someone with a body mass index above 30 and COPD. We believe that this scenario inappropriately disadvantages someone who should be prioritized for early access to a vaccine, and we recommend removing the criteria related to multiple conditions.

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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,

Mary B. Dwight
Chief Policy and Advocacy Officer
Senior Vice President of Policy and Advocacy
Cystic Fibrosis Foundation

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