December 21, 2020

José Romero, MD  
Chair, Advisory Committee on Immunization Practices (ACIP)  
1600 Clifton Road, NE  
Mailstop A27  
Atlanta, GA 30329

Re: CDC-2020-0124-0003, Advisory Committee on Immunization Practices (ACIP) December 18 and 20

Filed electronically at regulations.gov.

Dear Dr. Romero:

On behalf of the Cystic Fibrosis Foundation, thank you for this opportunity to provide additional comments on the Advisory Committee on Immunization Practices (ACIP) meeting that took place on December 19th and December 20th. We are aware of how challenging it has been for the ACIP and other decisionmakers to balance competing ethical principles and public health priorities as well as the urgency of improving health equity in vaccine distribution plans, and we thank committee members for the many thoughtful discussions regarding COVID-19 vaccine allocation. Following yesterday’s discussion on high-risk medical conditions, the CF Foundation would like to further urge the ACIP and other federal and state decisionmakers to include prioritization for rare disease populations for whom there is less evidence on the risks of COVID-19 infection compared to larger disease groups and additionally include allowances for clinician discretion in allocation recommendations.

We are pleased to see that the committee included persons aged 16 to 64 years with high-risk medical conditions in final recommendations for Phase 1c. We want to again stress that rare disease communities require distinct consideration. The Centers for Disease Control and Prevention’s (CDC) designation of CF as a condition that may increase the risk of severe disease from COVID-19 is due, in part, to a lack of evidence—which is unavoidable for a rare disease. As a small patient population, it has been challenging to gain a clear picture about how COVID-19 affects people with CF. In the case of CF, we believe this designation may mischaracterize the true risk for some people living with the disease, especially those with advanced lung disease and those who are post-transplant.

As decisionmakers provide more specificity on which diseases will be prioritized, we urge the ACIP to ensure allocation to both diseases with large populations capable of generating clear evidence of risk of severe COVID-19 illness and other rare disease populations too small to generate similar evidence. We ask ACIP and other decisionmakers at the federal and state level to take a broad definition of high-risk medical conditions based on the CDC’s list and allow for clinician discretion in identifying additional individuals at high-risk for prioritization purposes.
Once again, we thank you for your attention and consideration of people with CF as you tackle these difficult issues. These are important opportunities for collaboration and discussion regarding the ACIP’s work to support public access to safe and effective COVID-19 vaccines, and we stand ready to work alongside the committee in this endeavor.

Sincerely,

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