

CDC ACIP February 2021 Meeting

Speech for Dr. Albert Faro

Good afternoon. My name is Dr. Albert Faro, and I am the Vice President of Clinical Affairs at the Cystic Fibrosis Foundation. On behalf of the Foundation and the more than 30,000 people with CF in the US, I would like to thank the committee for the opportunity to provide comments regarding development and allocation of COVID-19 vaccines.

The CF Foundation is a national organization actively engaged in the research and development of new therapies for CF – a rare, life-threatening genetic disease characterized by thick, sticky mucus in the lungs resulting in frequent acute and chronic respiratory infections.

These chronic airway infections are punctuated by pulmonary exacerbations – events often triggered by respiratory viral infections that are a risk factor for an irreversible decline of lung function and associated with morbidity and mortality. Continued progression of the disease can result in advanced lung disease so severe that lung transplantation may be the only life extending option.

COVID-19 represents a serious threat for people with CF. The CF Foundation Patient Registry collects information on the health status of people with cystic fibrosis who receive care in CF Foundation-accredited care centers. The data underscores the threat this infection poses to people with CF. A published global analysis of 181 COVID-19 cases among people with CF demonstrated that CF patients with advanced lung disease and those who are post-lung transplantation are at increased risk of severe outcomes, including death.

We recognize that, to date, the ACIP included those with high-risk conditions as a prioritized group in the committee's COVID-19 vaccine allocation recommendations and we are pleased that these recommendations are accompanied by language from the CDC about using individual clinical judgement to identify patients whose risks factors warrant priority vaccine access. However, we are deeply concerned about the wide range of interpretations of ACIP's recommendations among states and localities, in some cases not including rare diseases like CF on lists of prioritized populations and in other cases opting to use age based criteria alone. The desire for simplicity must not come at the expense of those who are most vulnerable to the consequences of this infection. People with CF and others with high-risk conditions must be prioritized for early access. Some current state and local practices run counter to ACIP's intent of prioritizing those at highest risk of morbidity and mortality and are placing people with CF and other underlying medical conditions at greater risk solely for the sake of expediency.

We urge the ACIP to provide clarifying language on phase 1c recommendations for rare disease populations to ensure that high-risk patients with diseases like CF are able to gain early access to COVID-19 vaccines.

Thank you again for your attention and consideration of people with CF as you tackle these critical issues.