



October 13, 2021

Ms. Denise Kelly
Preparedness Program Director
Kansas Department of Health and Environment
Curtis State Office Building
1000 SW Jackson
Topeka, Kansas 66612

Dear Ms. Denise Kelly:

On behalf of those living with cystic fibrosis in Kansas, we write today to comment on the state's document entitled "Guidelines for the Use of Modified Health Care Protocols in Acute Care Hospitals During Public Health Emergencies".¹ We recognize the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable during the COVID-19 pandemic. However, we are concerned that Kansas' guidelines contain a reference to people with severe chronic lung disease that relies on outdated information about life expectancy and could prevent people with CF from receiving life-sustaining care during the ongoing public health emergency.

Kansas's guidelines exclude people with severe chronic lung disease, including patients with FEV₁ less than 25%, from admission or transfer to critical care and from access to scarce life-saving resources. The guidelines state that "exclusion criteria are intended to identify and exclude patients with a short life expectancy irrespective of the current acute illness" and categorize those with severe chronic lung disease as having a short life expectancy of six months or less.

While decisions about who receives treatment should never be based on underlying diagnoses, these criteria are also based on an inaccurate understanding of the current survival outcomes for the CF patient population. The outlook has dramatically improved in recent years for patients living with cystic fibrosis, even those with low lung function, thanks to recent advances in care and treatment options.² In fact, the median survival for patients with CF with an FEV₁ of less than 30 percent was shown to be 6.5 years.³ We expect that the introduction of new and transformational therapies like Trikafta™, which treats the underlying cause of the disease, will only further improve life expectancy.

Moreover, preliminary data from the CF patient registry—which collects data from accredited CF care centers and captures between 80 and 84 percent of CF patients in the US—shows that of the nearly 1,900 confirmed cases of COVID-19 among people with CF, only 14 are known to have died from complications related to COVID-19. This includes 116 patients with advanced lung disease, defined as those with a FEV₁ less than 40 percent predicted, and 129 patients post-lung transplantation.

¹ https://www.kdheks.gov/cphp/download/Crisis_Protocols.pdf

² <https://www.atsjournals.org/doi/pdf/10.1164/rccm.202004-0999LE>

³ <https://www.ncbi.nlm.nih.gov/pubmed/28115168>

Excluding patients with an FEV1 less than 25% could result in denial of life-saving care for patients with CF who seek treatment while the guidelines are active. Every patient with CF must be evaluated and triaged for COVID-19 treatment on a case-by-case basis based on their clinical presentation. Therefore, we urge Kansas to revise its guidelines to remove the references to severe chronic lung disease and short life expectancy in the exclusion criteria. Additionally, where feasible, we urge Kansas to create triage guidelines that leverage available disease-specific experts on site to ensure assessments tied to allocation determinations include the best available objective medical evidence.

State triage guidelines that are transparent and ensure equitable access to scarce resources are an important tool for protecting both care providers and patients in this difficult time. We look forward to working with you as you continue to revise the crisis standards of care guidelines for your state.

Sincerely,

Mary B. Dwight

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