



November 29, 2021

Ms. Jill Hunsaker Ryan, Executive Director
Dr. Eric France, Chief Medical Officer
Colorado Department of Public Health and Environment (CDPHE)

Dear Director Ryan, Dr. France, and Members of the GEEERC:

On behalf of those living with cystic fibrosis in Colorado, we write to comment on the state's document entitled "Crisis Standards of Care for Hospitals for the COVID-19 Pandemic".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, and applaud the Governor's Expert Emergency Epidemic Response Committee (GEEERC) for continuously reviewing its guidelines. However, we are concerned that Colorado's current CSC guidelines for hospitals contain a reference to people with chronic pulmonary disease that relies on outdated information about life expectancy and could prevent people with CF from receiving life-sustaining care during the ongoing public health emergency.

The tiering system employed by Colorado's guidelines involves the determination of a patient's triage score, which is based on their short and near-term survivability and measured by the Sequential Organ Failure Assessment (SOFA) and modified Charlson Comorbidity Score (mCCI) systems. The latter system, meant to predict 1-year survival, assigns a higher score to individuals with chronic pulmonary disease, defined as "any pulmonary disease requiring chronic supplemental oxygen therapy, FEV1 < 40% predicted, TLC < 60% predicted", and therefore deprioritizes them for access to scarce resources.

While decisions about who receives treatment should never be based on underlying diagnoses, these criteria are based on an inaccurate understanding of the current survival outcomes for the CF population. The outlook has dramatically improved in recent years for patients 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 last year, and 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.³

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 over 2,150 confirmed cases of COVID-19 among people with CF, only 17 are known to have died from complications related to COVID-19; this includes 140 patients with advanced lung disease, defined as those with an FEV1 less than 40 percent predicted, and 155 patients post-lung transplantation.

¹ <https://drive.google.com/file/d/17H1i3FljgXHAXFTiCoiTgxBrFpdnpMGQ/view>

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

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

Deprioritizing patients with chronic pulmonary disease and those with an FEV1 less than 40 percent predicted could result in the denial of life-saving care for patients with CF who seek treatment should the guidelines be activated. Furthermore, the use of the SOFA scoring system in the guidelines may have an unintended discriminatory impact against people with disabilities if reasonable modifications are not made to account for those with a baseline level of impairment prior to the acute care episode.

We urge Colorado to revise its guidelines to remove the reference to chronic pulmonary disease and allow for reasonable modifications to SOFA to ensure every patient is evaluated and triaged for COVID-19 treatment on a case-by-case basis based on their clinical presentation. Additionally, where feasible, we urge Colorado to create guidelines that leverage available disease-specific experts on site to ensure assessments are 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 and improve Colorado's crisis standards of care guidelines.

Sincerely,

Mary B. Dwight

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Cc: Members of the Governor's Expert Emergency Epidemic Response Committee (GEEERC)