



April 15, 2020

Azita G. Hamedani, MD, MPH, MBA
Chair, State Disaster Medical Advisory Group
Sent by email: agh@medicine.wisc.edu
UW Hospitals and Clinics
600 Highland Avenue
Madison, WI 53792

Re: Report and Recommendations of the Ventilator Allocation Advisory Workgroup

Dear Dr. Hamedani,

On behalf of those living with cystic fibrosis in Wisconsin, I write to comment on the state's proposed ventilator allocation guidelines. We are concerned that Wisconsin's proposed allocation plan inappropriately discriminates against people with CF and may prevent them from receiving life-sustaining care during the current COVID-19 pandemic.

All human life is valuable, and we are heartbroken to know that clinicians and caretakers on the front lines of this pandemic may be forced to consider unthinkable choices as they care for their patients. While we recognize the importance of giving frontline healthcare workers guidance during the crisis, it is critical that any state plan for allocating scarce medical resources ensures that *all* patients receive individualized assessments based on the best available medical evidence—regardless of underlying health conditions.

On March 28, the Office for Civil Rights (OCR) at the US Department of Health and Human Services issued a bulletin regarding Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19).¹ In the bulletin, OCR reminded federally-funded health programs and activities that Section 1557 of the Affordable Care Act and Section 504 of the Rehabilitation Act prohibit discrimination on the basis of disability, and that these civil rights laws are still in effect. OCR stated, "Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."

We are concerned that the proposal under consideration by the State Disaster Medical Advisory Group uses the mere presence of underlying conditions, including chronic lung disease and lung capacity, as a determining factor in whether a patient will have access to limited medical resources. The proposal includes reference to patients who have end-stage organ failure and are transplant ineligible, including patients with severe chronic lung diseases with FEV₁ <25%, in the second tier—meaning that these

¹ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

patients would be deprioritized for access to ventilators in the case that a shortage required moving to the second triage stage. Additionally, patients who have end-stage organ failure and are transplant eligible with severe chronic lung disease are listed in the third tier— deprioritizing these patients for access to ventilators when moving into the third triage stage due to lack of available resources. These categorizations could result in denial of life-saving care for patients with CF who seek treatment while the plan is active, solely based on their underlying condition.

The presence of CF should never disqualify someone from receiving care; decisions about who receives care should be based on the patient’s likelihood of benefitting from a treatment. CF manifests differently in every person, and no two CF patients can be measured by the same yard stick. Additionally, the outlook has dramatically improved in recent years for patients living with CF, thanks to continued advances in care and treatment options. Those living with advanced lung disease have improved outlooks; median survival for patients with CF with an FEV₁ <30% is currently over 6.5 years.² Furthermore, there is no evidence to suggest that people with CF cannot make a full recovery from COVID-19. Every patient with CF must be evaluated and triaged for COVID-19 treatment on a case-by-case basis consistent with how the general population is assessed.

State triage plans 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 urge the State Disaster Medical Advisory Group to carefully evaluate the proposal at hand and remove harmful language that excludes certain patients from receiving care solely because of an underlying condition.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary Dwight', with a stylized flourish at the end.

Mary Dwight
Chief Policy and Advocacy Officer
Cystic Fibrosis Foundation

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