



April 22, 2020

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To whom it may concern:

On behalf of those living with cystic fibrosis in Vermont, I write to comment on the state's document entitled "Vermont Crisis Standards of Care Plan."<sup>1</sup> We appreciate this opportunity to provide input and recognize the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable during this crisis. However, we are concerned that Vermont's mechanical ventilation and external oxygenation allocation plan uses the existence of underlying conditions to determine who receives treatment and may prevent people with CF from receiving life-sustaining care during the current Coronavirus Disease 2019 (COVID-19) pandemic.

All human life is valuable, and we are heartbroken 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 healthcare workers guidance during this crisis, it is critical that plans for allocating scarce medical resources ensure all patients are evaluated on a case-by-case basis and decisions about who receives treatment are based on current clinical presentation – 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, the Health Insurance Portability and Accountability Act, and COVID-19.<sup>2</sup> 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 Vermont's plan, as currently written, uses the mere presence of existing health conditions – including cystic fibrosis and preexisting lung disease – as a determining factor in deciding which patients receive ventilators and external oxygenation in the event that limited supply requires rationing of care. The plan contains reference to severe chronic lung diseases, including people with cystic fibrosis requiring continuous home oxygen use prior to onset of acute illness, when determining

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<sup>1</sup> <https://www.healthvermont.gov/sites/default/files/documents/pdf/VT%20CSC%20Plan%2007-23-2019%20Final.pdf>

<sup>2</sup> <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

whether resources like ventilators and external oxygenation should be re-allocated. Such decisions could result in the denial of life-saving care for patients with CF who seek treatment while the plan is active, solely based on their underlying conditions – even though there is no evidence to suggest that people with CF cannot make a full recovery from COVID-19.

While decisions about who receives treatment should never be based on underlying diagnoses, this criterion is also based on an inaccurate understanding of the current survival outcomes for the CF patient population and does not factor in the short- and long-term impact of disease-modifying therapy. 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. The median survival for patients with CF with an FEV1 of less than 30% is 6.5 years.<sup>3</sup> 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. As such, every patient with CF must be evaluated and triaged for COVID-19 treatment on a case-by-case basis based on their clinical presentation.

We urge Vermont to revise its current plan, being careful to avoid any language that unfairly disadvantages those with underlying conditions like cystic fibrosis. Guidelines for determining which patients receive scarce resources should be developed in consultation with relevant stakeholders, including patient representatives and disease-specific experts, to ensure that the resulting recommendations are equitable and based on the most recent data. Additionally, where feasible, we urge Vermont to create triage plans that leverage available disease-specific experts on site to ensure assessments tied to allocation determinations include the best available objective medical evidence.

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. Thank you again for this opportunity to comment on Vermont's plan. We look forward to working with you as you continue to revise the crisis standards of care plan for your state.

Sincerely,

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<sup>3</sup> <https://www.atsjournals.org/doi/pdf/10.1164/rccm.202004-0999LE>