



May 8, 2020

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Submitted by e-mail at: Denise.L.Kelly@ks.gov, KDHE.Preparedness@ks.gov

Dear Denise Kelly:

On behalf of those living with cystic fibrosis in Kansas, we write today to thank you for removing the Kansas Department of Health and Environment's "Toolkit for COVID-19"<sup>1</sup> from the state website. We recognize the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable during the ongoing Coronavirus Disease 2019 (COVID-19) pandemic. In place of the state's former toolkit, we urge you to adopt crisis standards of care guidelines that do not use diagnosis alone to determine who receives care and protects people living with chronic conditions.

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 guidelines 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."

Kansas' toolkit would have allowed hospitals to exclude patients with severe chronic lung disease with post-bronchodilator FEV1 less than 25 percent predicted or baseline PaO2 less than 55 mm Hg from admission or transfer to critical care and from access to scarce life-saving resources. If implemented, the toolkit could result in denial of life-saving care for patients with CF who seek treatment while the document is active, solely based on their underlying condition – even though there is no evidence to suggest that people with CF cannot make a full recovery from COVID-19.

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<sup>1</sup> Guidelines contained in the Toolkit for COVID-19: <https://assets.documentcloud.org/documents/6824976/Kansas-Modified-Protocols-for-Hospitals-in.pdf>

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

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 and do 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.<sup>3</sup> In fact, the median survival for patients with CF with an FEV<sub>1</sub> of less than 30 percent was shown to be 6.5 years.<sup>4</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.

In fact, preliminary data from the CF patient registry—which collects data from accredited CF care centers and includes 97 percent of CF patients in the US—shows that there has only been one death among the 25 confirmed cases of COVID-19. This includes four patients with advanced lung disease, defined as those with a FEV<sub>1</sub> less than 40 percent predicted, and three patients post-lung transplantation. Additionally, an article published in the Journal of Cystic Fibrosis reported that of the 40 cases across eight countries, 70 percent have already recovered.<sup>5</sup>

Once again, we thank Kansas for removing the toolkit from the state website and urge the state to adopt equitable crisis standards of care guidelines that protect those living 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 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.

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

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pubmed/28115168>

<sup>5</sup> [https://www.sciencedirect.com/science/article/pii/S1569199320301259?dgcid=rss\\_sd\\_all](https://www.sciencedirect.com/science/article/pii/S1569199320301259?dgcid=rss_sd_all)