



October 18, 2021

The Honorable Jeanette Nunez
Lieutenant Governor of the State of Florida
The Capitol, 400 S. Monroe St.
Tallahassee, FL 32399

Dear Lieutenant Governor Nunez:

On behalf of those living with cystic fibrosis in Florida, we write today to ask that the state of Florida act now to adopt crisis standards of care guidelines that clearly direct health care providers across the state to refrain from discriminating against people with underlying conditions and disabilities, including those with cystic fibrosis, in the provision of treatment during the COVID-19 pandemic. We recognize the monumentally difficult task public health officials face when creating allocation guidelines that are both equitable and actionable, and we stand ready to serve as a resource to the state in any way we can.

Statewide guidance needed during the COVID-19 pandemic

COVID-19 continues to present serious risk to Florida residents, including those with cystic fibrosis. According to publicly available data from the CDC, as of October 17th, over 722,000 people in the United States have died as a result of COVID-19, including more than 57,000 in Florida. Furthermore, over the last seven days, more than 18,700 cases in Florida have been reported to the CDC—the second highest in the nation.¹ As the virus continues to spread, the capacity of our healthcare system will continue to be stressed. Despite recent declines in COVID-19 admission rates, there are several reports of hospitals across Florida near or at capacity.^{2, 3, 4} During these unprecedented times, it is important that healthcare workers have access to state-wide guidance on how to equitably allocate scarce medical resources – guidance that, to our knowledge, has not yet been adopted by the state of Florida. We fear that without such response, providers on the front lines will not be adequately equipped to make equitable choices about which patients receive life-sustaining care when need outstrips capacity.

Importance of individualized assessment

All allocation determinations must be based on individualized patient assessment rather than the mere presence of an underlying condition or disability, as described in a March 2020 bulletin issued by the US Department of Health and Human Services (HHS) Office of Civil Rights (OCR).⁵ In the bulletin, OCR states, “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 medical evidence.”

¹ <https://covid.cdc.gov/covid-data-tracker/#datatracker-home>

² <https://www.news-journalonline.com/story/news/coronavirus/2021/09/28/3-adventhealth-hospitals-volusia-county-still-exceed-capacity/5881590001/>

³ <https://www.wftv.com/news/local/orange-county/95-floridas-icu-beds-use-even-covid-19-cases-start-decline/7ZPCYSEEJJBXVLRNBESXSPCCH4/>

⁴ <https://www.nbcnews.com/health/health-care/never-ending-nightmare-hospitals-where-icu-hospitalizations-stayed-high-n1280318>

⁵ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>

As the virus continues to spread, it is imperative that the state develop and implement guidelines for how health care providers can protect patients from discriminatory practices and ensure equitable allocation of scarce medical resources. We urge Florida to adopt an equitable crisis standards of care plan that protects 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 Florida 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 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 plan for your state.

Sincerely,

Mary B. Dwight

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Cc: Simone Marstiller, Secretary, Agency for Health Care Administration (AHCA)
Dr. Joseph A. Ladapo, Surgeon General, State of Florida