



August 24, 2020

Governor Ron DeSantis
Governor of the State of Florida
The Capitol, 400 S. Monroe St.
Tallahassee, Florida 32399

Dear Governor DeSantis:

On behalf of the undersigned organizations representing people with chronic conditions and disabilities, thank you for your ongoing efforts to address the COVID-19 pandemic. We write today to follow up on our previous correspondence dated April 27, 2020, and to request 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 pre-existing conditions and disabilities in the provision of treatment during the COVID-19 pandemic.

COVID-19 continues to present serious risk to Florida residents, including the patients we represent. According to publicly available data from the CDC, as of August 24th, over 176,000 people in the United States have died as a result of COVID-19, including more than 10,300 in Florida.¹ Furthermore, over the last seven days, more than 26,900 cases in Florida have been reported to the CDC—the third highest in the nation. As the spread of the virus shows no signs of slowing down, the capacity of our healthcare system will continue to be stressed. Unfortunately, our state has reached a point where need outstrips capacity; we have heard recent reports of numerous Florida hospitals running out of intensive care beds to treat COVID-19 patients.^{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 resources, providers on the front lines will not be adequately equipped to make equitable choices about which patients receive life-sustaining care during the ongoing pandemic.

All allocation determinations must be based on individualized patient assessment rather than on the mere presence of an underlying condition or disability, as described in a March 28 bulletin issued by the

¹ <https://www.cdc.gov/covid-data-tracker/>

² <https://thehill.com/homenews/coronavirus-report/509636-at-least-50-florida-hospital-icubed-capacity>

³ <https://www.nbcnews.com/news/us-news/florida-hospitals-face-icu-bed-shortage-state-passes-300-000-n1233899>

⁴ <https://www.sun-sentinel.com/coronavirus/fl-ne-broward-hospitals-getting-overflow-20200728-akz7k5wmubb2billpnofsqtdy-story.html>

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 objective medical evidence.”

As Florida continues to experience one of the nation’s largest surges in COVID-19 cases, 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 you to work with our organizations, as well as other patient and disability rights organizations in Florida, to develop guidance in accordance with the OCR bulletin that ensures all patients are evaluated on a case-by-case basis and that decisions about who receives treatment are based on current clinical presentation – regardless of underlying health condition or disability. Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states.⁶ We hope this document helps the State of Florida draft guidance that is equitable and does not discriminate against the people we represent.

We look forward to working with you to develop guidelines for our state that safeguard the health and affirms the rights of those in Florida living with disabilities and pre-existing conditions. If you have any questions regarding this letter, or if we may provide further information, please don’t hesitate to contact Rachel Patterson with the Epilepsy Foundation at rpatterson@efa.org.

Sincerely,

American Kidney Fund
Arthritis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation Florida
National Multiple Sclerosis Society
National Organization for Rare Disorders

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

⁶ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf