



NORD®



EPILEPSY
FOUNDATION



May 1, 2020

The Honorable Phil Murphy
Governor of New Jersey
225 W. State St
Trenton, NJ 08625

Dear Governor Murphy:

On behalf of the undersigned organizations representing people with chronic conditions and disabilities, thank you for your considerable efforts to address the coronavirus (COVID-19) crisis. As COVID-19 continues to spread through our communities, we are facing unprecedented times. Unfortunately, our state may reach a point where need outstrips our health care capacity. This is a reality that we must face together. Our response cannot be based on discriminatory and outdated ideas about quality of life or the value of people with disabilities and chronic conditions to society.

Thank you for the work you have done and for all of your efforts to address this health care crisis. We value the thought and care that went into the development of the guidance called Allocation of Critical Care Resources During a Public Health Emergency released on April 11. We specifically appreciate that the plan does not use any categorial exclusion criteria based on diagnosis. However, we would like to highlight some of the concerns raised by Disability Rights New Jersey in their letter to you on April 16,¹ and ask that you continue to work with disability rights organizations and patient organizations like ours throughout this public health crisis.

We share the concern of Disability Rights New Jersey that the use of the Sequential Organ Failure Assessment (SOFA) and long-term survival standards may unfairly disadvantage the people we represent. The use of SOFA scores may have an unintended discriminatory impact against people with disabilities. People with life-limiting chronic conditions may be de-prioritized compared to others, even if they have the same likelihood for immediate survival. We encourage you to include reasonable modifications to the SOFA and other instruments to account for those with a baseline level of impairment prior to the acute care episode.

We urge you to work with our organizations, as well as disability rights organizations like Disability Rights New Jersey, throughout this crisis. 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

¹<https://static1.squarespace.com/static/5e8f69a0603f6633319de6ed/t/5ea0661e8cbfac380548b4bc/1587570257531/CommissionerDOH-FU04162020.pdf>

Coronavirus Disease 2019 (COVID-19).² Several of our groups have endorsed additional guidance, written by disability rights professionals, on how to implement the bulletin in states that may be helpful.³

We look forward to working with you to develop a plan for our state that safeguards the health and affirms the rights of New Jersey's residents 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 Diabetes Association
Arthritis Foundation
Crohn's & Colitis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders

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

³ https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf