



November 19, 2020

The Honorable Eric Holcomb
Governor of Indiana
200 W. Washington St.
Second Floor, Rm. 206
Indianapolis, IN 46204

Dear Governor Holcomb:

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 request that the state of Indiana 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 emergency.

COVID-19 continues to present serious risk to Indiana residents, including the patients we represent. As of November 18, 2020, over 247,000 people in the United States have died as a result of COVID-19, including more than 5,000 in Indiana.¹ Furthermore, over the last seven days, more than 42,800 cases in Indiana have been reported to the CDC.¹ Unfortunately, the need has begun to out weight the capacity in Indiana; we have heard recent reports of Indiana hospitals struggling to handle the surge of COVID-19 patients.² As the spread of the virus shows no signs of slowing down, the capacity of our health care system will continue to be stressed.

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 Indiana. 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.

As described in a March 28, 2020, bulletin issued by the U.S. Department of Health and Human Services (HHS) Office of Civil Rights (OCR), all allocation determinations must be based on individualized patient assessment rather than on the mere presence of an underlying condition or disability.² In the bulletin, OCR states, “decisions by covered entities concerning whether an individual is a candidate for treatment

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

² <https://www.indystar.com/story/news/health/2020/10/22/indiana-coronavirus-some-hospitals-struggle-surge-patients/5998921002/>

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

should be based on an individualized assessment of the patient based on the best available objective medical evidence.”³

As Indiana continues to experience a surge 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 Indiana, 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.² We hope this document helps Indiana draft and adopt guidance that is equitable and does not discriminate against the people we represent.

We look forward to working with you to develop guidelines that safeguard the health and affirms the rights of those in Indiana 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 Annissa Reed with the National Organization for Rare Disorders (NORD) at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

American Kidney Fund
Arthritis Foundation
Cystic Fibrosis Foundation
Epilepsy Foundation Indiana
National Multiple Sclerosis Society
National Organization for Rare Disorders
Pulmonary Hypertension Association

² https://www.centerforpublicrep.org/wp-content/uploads/2020/04/Guidance-to-States-Hospitals_FINAL.pdf