



August 6, 2020

The Honorable Jay Inslee
Office of the Governor
416 14th Ave SW,
Olympia, Washington 98504

Dear Governor Inslee,

On behalf of the 25-30 million Americans living with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for your considerable efforts to address the coronavirus (COVID-19) crisis. We write today to comment on the state's document titled "Proclamation 20-46.2, "High-Risk Employees – Workers' Rights"" and to express our concern that the updated guidance may unintentionally deny critical workplace protections needed by the rare disease patients that we represent.ⁱ

The COVID-19 pandemic has been particularly challenging for the rare disease community. Many rare disease patients are immune compromised, putting them at high risk of infection and serious illness. Proclamation 20-46.2 had offered important protections to these patients, by requiring employers to provide alternative work arrangements for high-risk employees with serious health conditions. However, amendments made to the state's proclamation on July 29, 2020, may now cause rare disease patients to be excluded.ⁱⁱ

The revised guidance creates two pathways through which employees may access workplace protections. First, individuals who are 65 years or older, or whose underlying medical conditions are listed by the Centers for Disease Control (CDC) as "at increased risk," are automatically entitled to accommodations. Second, the guidance states that individuals who "might be at increased risk," (as defined by CDC's list of underlying medical conditions) "may" qualify for accommodations if they obtain medical verification of such risk. NORD supports the intent of the proclamation to ensure that those at risk are not forced into a workplace situation that are unsafe. However, the updated guidance fails to extend such protections to many rare disease patients who would be able to prove that they are indeed at increased risk. It is important to note that the CDC's list of underlying medical conditions is evolving and based on published studies and data on COVID-19's interactions with individual diseases.ⁱⁱⁱ

Unfortunately, the current version of this list fails to capture the vast majority of the more than 7,000 known rare diseases. Due to the small patient populations, conclusive data about COVID-19's impact on many rare conditions may never be available, or will take significantly longer to amass, leaving these conditions absent indefinitely from the list. Consequently, the proclamation's reliance on this list will leave patients with rare diseases who indeed "might be at increased risk" due to the nature of their rare disease without the protections provided to other similarly situated patients.

Without these protections, individuals with significant rare health conditions are faced with a devastating choice: place their health at risk by going back to work or lose their jobs altogether. Rare disease patients are facing this decision now, and even if the CDC eventually includes some of those

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conditions on the “high risk” list, the delay could be life-threatening. To address this issue, NORD encourages the state to include rare disease patients within the definition of those that “might be at increased risk.” Through this process, an individual with a rare disease could gain access to the patient protections promulgated by Proclamation 20-46.2 following appropriate medical verification.

We look forward to continuing to work with alongside you and your staff to ensure that the issues and barriers faced by rare disease patients are taken into strong consideration in Washington state’s response to this crisis. For questions regarding NORD or the above comments please contact Corinne Alberts at calberts@rarediseases.org.

Sincerely,



Rachel L. Sher, J.D., M.P.H.
Vice President, Policy and Regulatory Affairs
National Organization for Rare Disorders

ⁱ Proclamation 20-46.2, (July 29, 2020) https://www.governor.wa.gov/sites/default/files/proclamations/proc_20-46.2.pdf?utm_medium=email&utm_source=govdelivery

ⁱⁱ Re: Proclamation 20-46.2, “High-Risk Employees – Workers’ Rights”. (July 29, 2020) https://www.governor.wa.gov/sites/default/files/Memo%20on%20High%20Risk%20Worker%20Proclamation.pdf?utm_medium=email&utm_source=govdelivery

ⁱⁱⁱ Centers for Disease Control. People with Certain Medical Conditions. Accessed on July 30, 2020. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fgroups-at-higher-risk.html

