



December 14, 2020

Ngozi O. Ezike, MD  
Director  
Illinois Department of Public Health  
535 West Jefferson Street  
Springfield, IL 62761

Dear Dr. Ezike:

On behalf of the LuMind IDSC Foundation and the National Down Syndrome Society (NDSS), the leading national Down syndrome research and advocacy organizations, we want to bring to your attention information about the risks facing people with Down syndrome as a result of COVID-19 and recommend how they should be included in your state's vaccine allocation framework.

NDSS is the leading human rights organization for all individuals with Down syndrome, and the largest nonprofit in the U.S. dedicated to advocating for individuals with Down syndrome and their families. LuMind IDSC is a nonprofit organization that accelerates research to increase availability of therapeutic, diagnostic, and medical care options for individuals with Down syndrome and their families.

Our organizations support the COVID-19 Vaccine Allocation Principles outlined by the Consortium for Citizens with Disabilities (CCD), which take into consideration the needs of people with disabilities and direct care workers across settings, ensure that both the information and the means of distribution are accessible, and comply with federal guidance and civil rights laws.<sup>1</sup>

Our organizations also generally support the recommendations of the CDC's Advisory Committee on Immunization Practices, which prioritize persons living in certain congregate living situations and with certain underlying conditions, based on CDC's listing of who is at increased risk. Down syndrome in and of itself is not currently on that list, but many persons with Down syndrome, due to where they live or their underlying health issues, need to be considered for early phase COVID-19 vaccine prioritization.

There are an estimated 210,000 Americans with Down syndrome. In addition to intellectual disability, people with Down syndrome have a variety of co-occurring medical conditions that contribute to medical complexity and place them at a disproportionately increased risk of having more severe outcomes following infection with COVID-19. In addition, many adults with Down

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<sup>1</sup> <http://www.c-c-d.org/fichiers/CCD-Vaccine-Allocation-Principles-October-2020.pdf>

syndrome live in community-based congregate settings such as group homes, which share many of the same risk factors as long-term care facilities where a significant portion of COVID-19 deaths have occurred.

The T21 Research Society (T21RS), an international non-profit scientific organization of researchers studying Down syndrome, recently released survey data comparing how COVID-19 is impacting people with Down syndrome versus the general population.<sup>2</sup> The survey shows so far that, while in the general population the risk for poor outcomes of COVID-19 increases around 60 years, in people with Down syndrome poor outcomes become more pronounced after age 40 and is increased in these older individuals compared to the general population of similar age.<sup>3</sup> In fact, the risk of death for an individual with Down syndrome after age 40 is equivalent to the risk of death for an individual without Down syndrome after the age of 80.<sup>4</sup>

Based on the survey results, T21RS strongly recommends that individuals with Down syndrome, particularly those over 40, and those younger than 40 with significant comorbidities, be prioritized for COVID-19 vaccination programs to limit SARS-Cov-2 infections.<sup>5</sup>

We urge you to take this information into consideration, and to expressly address the appropriate prioritization of individuals with Down syndrome as a high-risk population in your state's COVID-19 vaccine allocation plan.

Sincerely,



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<sup>2</sup> <https://www.t21rs.org/t21rs-statement-with-regards-to-vaccinations-for-people-with-down-syndrome-during-the-covid-19-pandemic/>

<sup>3</sup> <https://www.t21rs.org/wp-content/uploads/2020/02/TT21RS-shielding-statement.pdf>.

<sup>4</sup> <https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/>

<sup>5</sup> <https://www.t21rs.org/wp-content/uploads/2020/02/T21RS-vaccines.pdf>