



February 23, 2021

The Honorable Pete Ricketts, Governor of Nebraska  
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Mayor Leirion Gaylor Baird  
City of Lincoln, Nebraska  
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RE: Joint Letter to Protect Vulnerable Nebraskans with Down syndrome through the Nebraska COVID-19 Vaccination Plan.

Dear Governor Ricketts, Mayor Gaylor Baird, Director Lopez, Deputy Director Quintana-Zinn, and Ms. Smith:

Thank you for your efforts in developing the current COVID-19 Vaccination Plan. This must be a difficult time for all of you as you make critical decisions about the health and wellbeing of Nebraskans in response to the COVID-19 pandemic.

After reviewing the most recent research about the impact of COVID-19 on adults with Down syndrome and the implications for the current plan, the Down Syndrome Association for Families of Nebraska (DSAF) and the Down Syndrome Alliance of the Midlands (DSAM) come to you with grave concerns about one of the most vulnerable populations in Nebraska.

This past Thursday, hope was taken away from Nebraskans with Down syndrome and other high-risk medical conditions. Just as their turn-in-line arrived in the published Phase 1B vaccine prioritization, the state suddenly removed them from this category. Individuals with Down syndrome, for example, are ten times more likely to die if they contract COVID-19, due to multiple and more complex comorbidity factors.

Governor Ricketts stated that age was the single biggest factor in determining who is most likely to be severely impacted by the coronavirus. Research shows that irrespective of age, "In individuals with Down syndrome specifically, there is an estimated four-fold increase in risk for COVID-related hospitalization and a ten-fold increase in mortality." (AADMD, 2020). Therefore, the CDC guidelines were changed in December to reflect these important findings regarding risk. Similarly, the American Academy of Developmental Medicine and Dentistry, along with national disability and national Down syndrome organizations, prepared joint statements to strongly advocate for vaccine allocation and distribution frameworks to specifically include people with Down syndrome and their caregivers as high priority, given their disproportionately high level of risk. Based on this research about the vulnerability of all adults with Down syndrome, states like Ohio, Oregon, Missouri, and about 37 others, have already modified their vaccine allocation distribution plans to prioritize these individuals into Phase 1B.

However, according to last week's sudden revision to the current Nebraska COVID-19 Vaccination Plan, adults under 65 with high-risk medical conditions, including Down syndrome, would no longer be eligible for vaccines in Phase 1B. This means that critical workforce employees (e.g. teachers, janitorial staff, and food processors) included in Phase 1B – who are vital but who likely have a much higher survival rate – would have access to vaccines before adults with Down syndrome.

We know that Nebraska leadership values people with developmental disabilities and seeks to protect our most vulnerable citizens. In 2016, Governor Ricketts signed into law the Down syndrome Diagnosis Information and Support Act (LB891) as a key piece of legislation to require doctors to provide current reference information to new and expectant parents of a child with Down syndrome, compiled by DHHS in coordination with Down syndrome organizations in the state. Many individuals with Down syndrome in Lincoln and Omaha were involved in providing supportive testimony and attended the bill signing (see the picture below of DSAF member, Elissa, shaking hands with the Governor in appreciation for this new law).

The DSAF and DSAM are the two largest 501(c)(3) organizations serving individuals with Down syndrome in Lincoln, Omaha, and the entire state of Nebraska. Together, both organizations support nearly 600 people with Down syndrome and several thousand families throughout the entire state of Nebraska.

Based on the research and recommendations, DSAF and DSAM suggest the following amendments and clarifications for Nebraska's COVID-19 Vaccination Plan as a way to better protect people at such high risk:

1. Given the disproportionately high mortality rate, we recommend specifically re-adding adults with Down syndrome, who are 16 and older, back into the higher priority Phase 1B, as about 40 states have done.
2. We would also like to clarify, as was done recently in the state of California, that family members or Caregivers of individuals with Down syndrome should also be added into Phase 1B for the same risk mitigation reasons outlined.

Please consider incorporating these proposed amendments. You are leaders who can make a tremendous impact in protecting Nebraska's most vulnerable citizens. If you have further questions, please contact Jamie Bertucci, Executive Director of the Down Syndrome Association for Families of Nebraska, at 402-421-1338 or [director@dsafnebraska.org](mailto:director@dsafnebraska.org).

Best Regards,

The Down Syndrome Association for Families of Nebraska (DSAF) – Lincoln, Nebraska  
Jamie Bertucci, Executive Director  
The DSAF Board of Directors

Down Syndrome Alliance of the Midlands (DSAM) – Omaha, Nebraska  
Leah Janke, Executive Director  
The DSAM Board of Directors

Global Down Syndrome Foundation (GLOBAL) – Headquartered in Denver, Colorado  
Michelle Sie Whitten, President & CEO  
The GLOBAL Affiliates & Staff

National Down Syndrome Congress (NDSC) – Headquartered in Georgia  
David Tolleson, Executive Director  
Heather Sachs, Policy & Advocacy Director





Research Reference Links:

- (1) <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html#downsyndrome>
- (2) <https://www.theguardian.com/world/2020/nov/28/extremely-vulnerable-in-uk-given-high-priority-for-coronavirus-vaccine>
- (3) Espinosa JM (2019) Transcriptional CDKs in the spotlight. *Transcription* 10(2):45-46. [https://www.cell.com/cell-reports-medicine/pdf/S2666-3791\(20\)30024-0.pdf](https://www.cell.com/cell-reports-medicine/pdf/S2666-3791(20)30024-0.pdf)
- (4) <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerablepersons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#cev>
- (5) <https://www.dw.com/en/covid-german-regulations-on-who-gets-vaccine-first/a-55987647>