December 18, 2020

Centers for Disease Control and Prevention
1600 Clifton Road, N.E.
MS H24-8
Atlanta, GA 30329

**Docket No. CDC-2020-0124: December 20, 2020 ACIP Meeting**

Dear Sir or Madam:

Thank you for the opportunity to submit comments on behalf of the National Organization for Rare Disorders (NORD) regarding the Advisory Committee on Immunization Practices (ACIP) Public Meeting on December 20. Founded in 1983, NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services for the one in ten Americans afflicted with a rare disorder. Throughout the COVID-19 pandemic, NORD has advocated for policies and implemented programs to ensure that the unique needs of the rare disease community are being met.

The COVID-19 pandemic has been particularly challenging for the rare disease community. Many rare disease patients are immunocompromised, putting them at high risk of infection and serious illness. However, due to small patient populations, conclusive data about COVID-19's impact on patients with various rare conditions is not currently available and may never become available. As a result, many rare disease patients feel particularly vulnerable and unsure of their place in the conversation around vaccine prioritization.

As the ACIP discusses prioritization for Americans with high-risk medical conditions, NORD presumes the ACIP will draw from the CDC web page, "People with Certain Medical Conditions," that outlines conditions with degrees of risk.[1] The CDC's list of underlying medical conditions that expose patients to a higher risk of contracting COVID-19 is evolving based on published studies and available data on the impact of COVID-19 on individuals with certain diseases.[2] However, as previously stated, due to very small patient populations, there is little or no published data available on the impact of COVID-19 on individual rare diseases. Consequently, the ACIP's reliance on this list might inadvertently leave behind rare disease patients who indeed "are at an increased risk" or "might be at increased risk" due to the nature of their rare disease, simply because of a lack of data.

At the December 20 meeting regarding Phase 1 allocation of COVD-19 vaccines, NORD requests that the ACIP specifically consider rare disease patients in their discussions around adults with "high risk" medical conditions. NORD fully recognizes that not every rare disease

[1] Centers for Disease Control. People with Certain Medical Conditions. Accessed on December 17, 2020. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html
[2] Ibid.

subjects patients to a higher risk of contraction or development of serious complications from COVID-19. However, we urge ACIP to encourage states to establish a mechanism that allows a health care provider to make a determination on the patient's inclusion in a specific immunization group if the rare disease patient is at high risk, even if their condition is not on either a CDC or ACIP list of conditions for Phase 1 prioritization.

NORD fully supports the allocation of vaccines in a way that is supported by science. Still, it is critical that there be a mechanism for patients who have rare diseases that may not be reflected on the CDC's evolving list of risk factors to be able to demonstrate their need for COVID-19 vaccines, along with other patients at high risk, as determined by the CDC.

On behalf of our over 300 member groups and 30 million Americans with a rare disease, NORD thanks the ACIP for the opportunity to submit comments and for the time and consideration they are putting into this incredibly important effort. For questions regarding NORD or the above comments, please contact me at rsher@rarediseases.org or 202-588-5700.

Sincerely,

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