



Make today a breakthrough.

January 26, 2021

Rochelle P. Walensky, MD, MPH
Director, Centers for Disease Control and Prevention (CDC)
1600 Clifton Road, NE
Building 21, 8th Floor
Atlanta, Georgia 30333

Dear Director Walensky,

As the leading national organization that represents children and adults with spinal muscular atrophy (SMA), a neuromuscular disease that commonly leads to respiratory failure and hospitalizations, **Cure SMA asks that the CDC elevates individuals with SMA in the priority distribution of COVID-19 vaccines.** Individuals with SMA represent a high-risk population for serious illness from COVID-19. Providing this population with immediate priority access to COVID-19 vaccines also reflects a key goal of the COVID-19 strategy released by the Biden Administration.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 U.S. births and approximately 1 in 50 people is a genetic carrier for SMA. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

Cure SMA was pleased that the Biden Administration's National Strategy for the COVID-19 Response and Pandemic Preparedness recognizes the impact of COVID-19 on high-risk populations, such as individuals with SMA.ⁱ Goal 6 of the Biden Administration strategy focuses on protecting and supporting those most at risk. The goal directs the CDC to *"develop and update clear public health guidance for such high-risk populations and settings to further minimize the risk of COVID infection, and work with states to update their pandemic plans to incorporate such guidance as necessary."* As part of that review, Cure SMA asks that individuals with SMA receive immediate access to available COVID-19 vaccines given their underlying health conditions and high risk for severe COVID-19 illness.

Cure SMA shared our views and SMA background to the CDC's Advisory Committee on Immunization Practices (ACIP) through public written testimony.ⁱⁱ In addition, Cure SMA joined other national disability and rare disease organizations in seeking priority access for high-risk populations, such as SMA, to COVID-19 vaccines.ⁱⁱⁱ While we recognize the complexity involved in developing distribution guidelines, we were disappointed that ACIP did not specifically identify SMA in their tiered proposal. In addition, we view the CDC's list of certain underlying medical conditions at increased risk of severe illness from COVID-19 as being narrow and incomplete.^{iv}

Individuals with SMA are at a high risk of serious illness from COVID-19 due to the neuromuscular and respiratory muscle weakness associated with SMA. As such, the SMA community has carefully followed CDC guidelines and Cure SMA recommendations to avoid public and social outings and gatherings. The SMA community's discipline and adherence to stay-at-home and social distancing guidelines have resulted in fewer COVID-19 infections and hospitalizations. However, the SMA community has been greatly impacted by COVID-19 in other significant ways, including limits in accessing SMA-related services (47%), canceled or delayed health appointments (33%) and services (30%). In addition, individuals with SMA have forgone family and social outings and holidays to protect themselves, their families, and communities. These significant impacts are not reflected in the CDC's increased medical risk list.

Cure SMA asks that you fully consider the natural course and effects of SMA as well as the direct and in-direct consequences the COVID-19 pandemic has had on children and adults with disabilities. We believe that after a thorough review of this information, you will also conclude that the SMA community should receive immediate and priority access to available COVID-19 vaccines.

We appreciate the thoughtful strategy and actions of the Biden Administration to address the COVID-19 pandemic, including the expeditious and equitable distribution of COVID-19 vaccines. We wish you well in your new position and thank you for considering our recommendations in support of immediate vaccine access for the SMA community. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or maynard.friesz@curesma.org.

Sincerely,



Kenneth Hobby
President



Mary Schroth, M.D
Chief Medical Director

ⁱ National Strategy for the COVID-19 Response and Pandemic Preparedness, 2021, <https://www.whitehouse.gov/wp-content/uploads/2021/01/National-Strategy-for-the-COVID-19-Response-and-Pandemic-Preparedness.pdf>

ⁱⁱ Cure SMA's Testimony to CDC's Advisory Committee on Immunization Practices, August 25, 2020, <https://www.curesma.org/wp-content/uploads/2020/06/Cure-SMA-Seeks-COVID-Vaccine-Priority-for-SMA-Community.pdf>

ⁱⁱⁱ Cure SMA Joins National Rare Disease Organizations in Seeking Vaccine Priority, December 16, 2020, <https://www.curesma.org/wp-content/uploads/2020/12/Advocacy-All-State-COVID-19-Letters-12.16.20.pdf>

^{iv} People with Certain Medical Conditions, U.S. Centers for Disease Control and Prevention, December 29, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>