



August 25, 2020

Advisory Committee on Immunization Practices (ACIP)
c/o Centers for Disease Control and Prevention
1600 Clifton Road, N.E., Mailstop H24-8
Atlanta, GA 30329-4027

Dear Members of the Advisory Committee on Immunization Practices:

Thank you for the opportunity to share Cure SMA's perspective on why high-risk populations, such as individuals living with spinal muscular atrophy (SMA), should receive priority access to available COVID-19 vaccines. As the leading national organization that represents children and adults with SMA and their families, **Cure SMA urges the Advisory Committee on Immunization Practices (ACIP) to recommend that individuals with SMA be included in the earliest priority group for COVID-19 vaccinations.**

SMA is a progressive neurodegenerative disease that impacts 1 in 11,000 births in the United States among all races, ethnicities, and genders. SMA robs people of physical strength and impedes their ability to walk, swallow, and—in the most severe cases—even breathe.

Cure SMA agrees with the ACIP COVID-19 Vaccines Work Group proposal to prioritize vaccine allocation and distribution to essential workers and high-risk populations, such as individuals with SMA.ⁱ The SMA community is at greater risk of serious illness from COVID-19 due to generalized neuromuscular weakness and especially respiratory muscle weakness that can progress to respiratory failure during a viral illness. In addition, COVID-19 has been especially disruptive for individuals with SMA and their ability to access essential services, educational supports, and other community opportunities. Individuals with SMA saw appointment cancellations or delays for their SMA-related care (42%), therapies (41%) and treatment (18%) due to COVID-19.ⁱⁱ Timely access to care, therapies, and treatment is critical for increasing and maintaining independence, physical strength, and daily living activities. *"The pandemic has certainly had an impact on families who have complex medical needs,"* one Cure SMA family wrote with her survey response.

The August 2020 Cure SMA survey also revealed that 45% of respondents reported concerns that they will catch COVID-19.ⁱⁱⁱ Cure SMA has recommended that individuals with SMA and their families continue their precautions through the rest of 2020 and into 2021 to avoid unnecessary exposure given they are a high-risk population. This recommendation is unlikely to change until we see a significant and sustained drop in cases or a vaccine becomes available.

The high health, social, and economic costs of COVID-19 on individuals with SMA and their families make it vital that health care leaders and providers prioritize access for the SMA community to COVID-19 vaccines. Cure SMA also asks ACIP to include family members and in-home health care workers who assist individuals with SMA with activities of daily living in the earliest priority group for vaccination. Without special prioritization, individuals with SMA will likely face the same struggles to access vaccines as they face in finding personal protective equipment (PPE) and other sanitizing supplies necessary to safeguard against COVID-19.




Approximately 42% of individuals with SMA and their families reported challenges in obtaining masks, gloves, gowns, antibacterial wipes, and other PPE. More than two-thirds of survey respondents worried that there will be a shortage of medical supplies and treatment because of COVID-19.ⁱⁱ Priority access to a COVID-19 vaccine would help to alleviate this access issue, especially as SMA families are limiting their trips to public places, such as grocery stores and doctors' offices, to reduce exposure for their high-risk household.


Finally, Cure SMA offers itself as a public resource to distribute information and other resources to the SMA community regarding COVID-19 vaccines and vaccination. The ACIP COVID-19 Vaccines Work Group identified partnerships with community organizations as a best practice for reaching at-risk communities and for distributing informational resources. Cure SMA is a trusted source of information for the SMA community, which could help counter the Work Group's concern that high-risk groups for COVID-19 may distrust public health.ⁱⁱⁱ

Thank you for considering Cure SMA's views for prioritizing access to COVID-19 vaccines for individuals with SMA and their families. For more information, please contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,


Kenneth Hobby
President


Mary Schroth, M.D
Chief Medical Director


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ⁱ [COVID-19 vaccine prioritization: Work Group considerations](#), ACIP, July 29, 2020

ⁱⁱ Cure SMA COVID-19 Impact Study, August 2020

ⁱⁱⁱ [COVID-19 vaccine implementation](#), ACIP COVID-19 Vaccines Work Group, July 29, 2020