



Make today a breakthrough.

November 2020

Dear Provider,

As the leading national organization that represents individuals and families with spinal muscular atrophy (SMA), a rare neuromuscular disease, **Cure SMA asks that you provide priority access to COVID-19 vaccines to individuals with SMA as well as their families and in-home health care workers.**

On October 2nd, an Operation Warp Speed [committee](#) of medical experts released a national framework for ensuring equity in distribution, administration, and access to vaccines approved for the treatment of COVID-19. The [framework](#) recommended a four-phase approach for reducing severe morbidity and mortality and negative societal impact due to COVID-19 transmissions.

Within the top two phases, **priority access** to a COVID-19 vaccine was recommended for individuals with rare diseases, home health workers, and people who are at significantly higher risk due to comorbid and underlying conditions. ***SMA was specifically highlighted within the framework's public comment summary (Appendix A-7).*** The framework also recognized the valuable role of community health care providers in reaching people with preexisting conditions and other high-risk characteristics.

Many individuals with SMA experience unique and complex medical needs, including generalized neuromuscular and respiratory muscle weakness that can progress to respiratory failure during a viral illness. **When a vaccine becomes available, individuals with SMA should receive priority access to a COVID-19 vaccine given their underlying health conditions may put them at greater risk for serious illness and complications.** Also, we ask that their home health aides and family members (who often share caregiving duties) receive preferential access to a COVID-19 vaccine.

Thank you in advance for your support of individuals with SMA and their caregivers as you prepare for the distribution of COVID-19 vaccines.

Sincerely,

Handwritten signature of Kenneth Hobby in black ink.

Kenneth Hobby  
President

Handwritten signature of Mary Schroth in black ink.

Mary Schroth, M.D.  
Chief Medical Director