

COMPASS

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The Impact of COVID-19 on the SMA Community

At the outset of the Coronavirus (COVID-19) pandemic, Cure SMA was interested in measuring the impact of the novel virus on the spinal muscular atrophy (SMA) community. To do this, Cure SMA launched three separate surveys at various times throughout the ongoing pandemic, covering questions on demographics, diagnoses and symptoms of COVID-19, the virus' impact on receiving healthcare, treatment, and supplies, as well as its impact on employment and finances.

The first survey was launched on April 7, 2020, in tandem with a COVID-19 Support Package that offered essential items that were difficult to locate at the time. The second survey was released on July 29, 2020, in conjunction with an announcement around the Medical Alert Bracelet program for the SMA community. Then, most recently, on November 18, 2020, a third COVID-19 survey was initiated with a new COVID-19 Personal Protective Equipment (PPE) Package that is helping individuals with SMA and their families get what they need as the pandemic continues.

As of November 25, 2020, participants numbered 1,579, 428, and 643 survey completions for the first, second, and third COVID-19 surveys, respectively. Most of the surveys were completed by a parent of an individual with SMA. In the first survey, very few survey participants reported to being diagnosed with COVID-19, 0.33% (n=4). However, in the third survey, 2.6% (n=16) of survey participants reported having been diagnosed with COVID-19, and four of these individuals were hospitalized due to complications from the virus.

Additionally, the pandemic has made a substantial impact on the ability for members of the SMA community to receive timely SMA-related care or treatment. More specifically, 32.5% of SMA individuals have had a healthcare provider (or clinic) cancel or delay an appointment for SMA-related care, and 30.5% of individuals have had their SMA-related service (e.g., physical therapy) delayed or cancelled due to COVID-19, according to the most recent COVID-19 survey. Also, about 1 in 5 individuals have had their healthcare provider (or clinic) cancel or delay an appointment to administer their SMA treatment due to COVID-19 (see Figure 1).

IMPACT OF COVID-19 ON THE ABILITY FOR MEMBERS OF THE SMA COMMUNITY TO RECEIVE TIMELY SMA-RELATED CARE OR TREATMENT

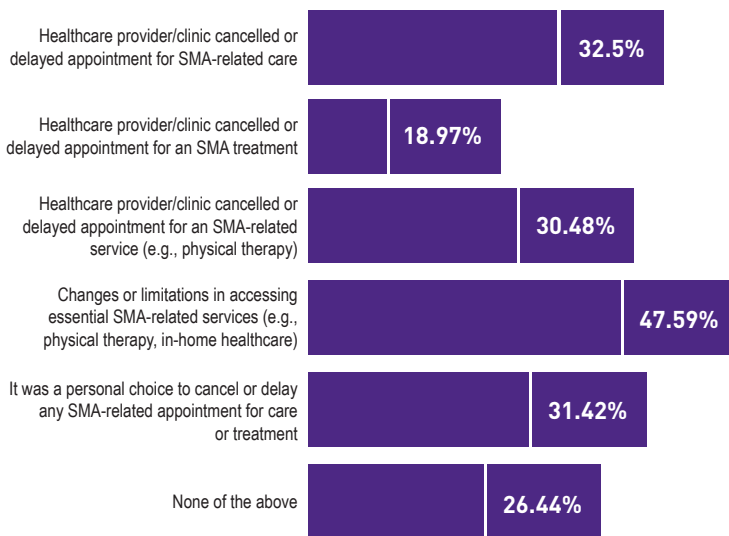


Figure 1: Impact of COVID-19 on the ability for members of the SMA community to receive timely SMA-related care or treatment. Participants were asked, "Has your child (or you, if affected with SMA) experienced any of the following due to COVID-19?" and were instructed to select all that apply.

COVID-19 has also impacted the employment and finances of the Cure SMA community. According to the most recent COVID-19 survey, 8.1% have lost their job and 63.3% have experienced anywhere from a little-to-severe financial hardship due to the pandemic.

Lastly, as COVID-19 cases continue to increase throughout the country, concerns have increased throughout the Cure SMA community. According to the second survey, 42.1% were concerned they will be diagnosed with COVID-19, but in the third survey, this concern has increased to 53.2%. Additionally, those worried about a shortage of medical supplies has increased from 60.1% to 75.0% in the most recent survey.

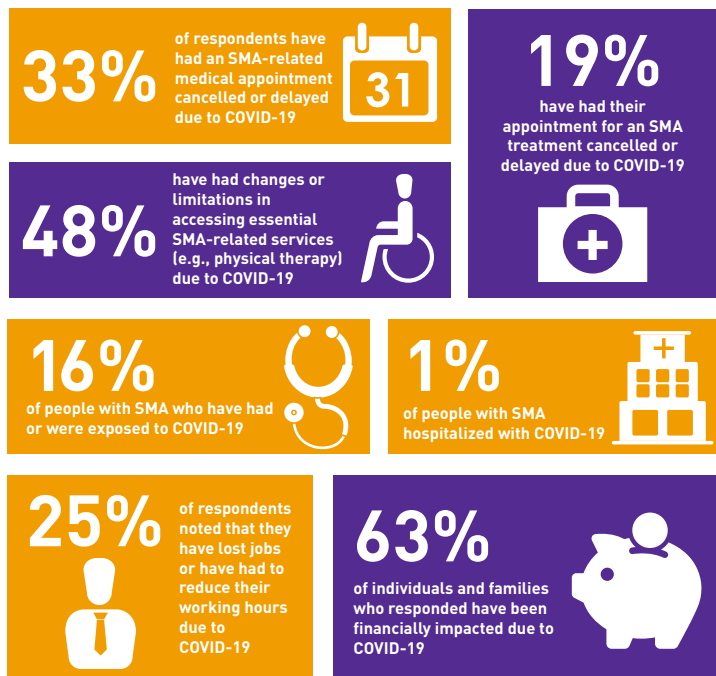


Figure 2: Between November 18, 2020 and November 25, 2020, 643 individuals with SMA, SMA caregivers, and SMA family members completed this follow up survey regarding the impact of COVID-19 on their daily lives dealing with SMA.

SMA and COVID-19: Guidance and Resources for Providers

As we continue to navigate the ongoing Coronavirus (COVID-19) pandemic, Cure SMA strives to ensure all individuals with spinal muscular atrophy (SMA) receive the best care possible.

The rise of COVID-19 remains an area of concern for many individuals with SMA. While little is known about the relationship and direct impact of COVID-19 on SMA, individuals with SMA have a higher risk of developing complications from viral respiratory infections. Therefore, Cure SMA continues to recommend that individuals with SMA and their families isolate, consistently wear masks and other personal protective equipment, and physically distance when isolation is not possible.

It is imperative that individuals with SMA and infants, children, and adults with suspected SMA receive prompt care and treatment. To facilitate safe and effective care, Cure SMA encourages the use of telemedicine when possible. In circumstances where telemedicine is not possible—such as procedures for the delivery of U.S. Food and Drug Administration (FDA) approved treatments

for SMA—healthcare providers are encouraged to work with individuals and families to limit any potential exposures in the healthcare setting, including pre-registration and limiting or avoiding waiting room time. Administration of available SMA treatments in a timely way is necessary to optimize health outcomes and prevent the rapid and irreversible effects of SMA. Thus, SMA treatments are essential procedures and dosing should not be delayed.

Additionally, the ongoing pandemic has significantly affected the delivery of pediatric care. The implementation of shelter-in-place and stay-at-home orders led to a decline in well-child visit and vaccination rates nationwide, ultimately causing delays in developmental screening and surveillance. In the absence of newborn screening for SMA, the clinical diagnosis of SMA relies heavily upon the recognition of early symptomatology by providers within the pediatric medical home. The suspected diagnosis of SMA is a medical emergency. Although the full impact of COVID-19 on diagnostic delays in SMA remains unknown, healthcare providers are encouraged to remain vigilant and to promptly evaluate for SMA via [genetic testing](#) upon suspicion.

To ensure care needs are met for the SMA community, Cure SMA has developed a template letter related to the delivery of care for patients with SMA during the COVID-19 pandemic, which can be found on the Cure SMA COVID-19 Information Center, available at <https://www.curesma.org/covid19/>. Additionally, we continue to advocate for priority access for COVID-19 vaccinations for individuals with SMA, with a full statement to healthcare providers available [here](#).

We encourage all members of the SMA community to utilize our prepared and templated letters, and welcome contact from healthcare providers looking for guidance and support at patientcare@curesma.org.

During the 2020 SMA Research & Clinical Care Meeting in June 2020, a round table presentation was given on the impact of COVID-19, as it relates to the care of patients with SMA. This program is accredited for 1.0 AMA PRA Category 1 Credit™ and can be accessed via the Cure SMA website. Please contact patientcare@curesma.org to access this program.

Cure SMA Advocates for Priority Access to COVID-19 Vaccine

**This article was written and published on December 18, 2020*

As vaccine manufacturers continue their work on the development and distribution of COVID-19 vaccines, Cure SMA continues to advocate for priority access for the spinal muscular atrophy (SMA) community now that the first Coronavirus (COVID-19) vaccines are approved by the U.S. Food and Drug Administration (FDA).

Two national committees of public health experts have been examining how to effectively and fairly allocate COVID-19 vaccines once available. The [Committee on Equitable Allocation of Vaccine for the Novel Coronavirus](#) was established through the Operation Warp Speed to make recommendations on the equitable allocation of a COVID-19 vaccine. Meanwhile, the Centers for Disease Control and Prevention’s (CDC) [Advisory Committee on Immunization Practices \(ACIP\)](#) is responsible for all vaccine recommendations, including those for COVID-19.

These committees have been meeting since this summer in public sessions to learn about the status of COVID-19 vaccine development and hear from health experts and advocates. Cure SMA participated in virtual meetings and [submitted testimony](#) to educate the committees about SMA and the health, social, and economic costs of COVID-19 on individuals with SMA and their families. Because respiratory and other common health factors associated with SMA put individuals with SMA at greater risk of serious illness from COVID-19, Cure SMA asked the committees to include the SMA community in their highest possible priority phase for receiving a vaccine.

In October, the Committee on Equitable Allocation of Vaccine for the Novel Coronavirus released a [four-phase framework](#) that puts individuals with rare diseases within the top two priority phases, depending on an individual’s circumstance. The Committee acknowledged the request of Cure SMA and other rare disease organization by including (on Page A-6 of the framework’s Appendix) the following: “Consider adding some language around rare diseases: spinal muscular atrophy; congenital heart defect; spleen disease; microscopic polyangiitis.”

Then, in December, prior to a COVID-19 vaccine approval, the ACIP approved its recommendations for Phase 1a of its [proposed phased allocation of vaccines for COVID-19](#), starting with healthcare workers and residents at long-term care facilities.

These recommendations represent a framework that will guide decisions at the state and local level. State and local public health officials will determine [distribution of the COVID-19 vaccine in their communities](#), which is why Cure SMA has also focused our advocacy in states, [educating Governors](#) early on in their planning process about the needs of the SMA community. Finally, we developed a resource for the SMA community to use to [self-advocate for access to COVID-19 vaccine](#) at the provider level.

The good news is that vaccines for COVID-19 are here, and Cure SMA believes that vaccination will be the best defense against this virus. However, while the current progress with COVID-19 vaccinations looks to be very positive, Cure SMA still strongly recommends that the SMA community continue the highest levels of isolation, especially during the winter virus season and during these highest peaks of the pandemic so far. Information about the COVID-19 vaccine and the SMA community can be found on the Cure SMA COVID-19 Information Center, available at <https://www.curesma.org/covid19/>.

ACIP PROPOSED PHASE 1 VACCINATION GROUPS

	Phase 1c Adults with high-risk medical conditions Adults aged 65+ years	
	Phase 1b Essential workers <i>(E.g., education sector, food and agriculture, utilities, police, firefighters, corrections officers, transportation)</i>	
Phase 1a Healthcare personnel Long-term care facility residents		

Source: Modified from ACIP COVID-19 Vaccines Work Group graphic