

Cure SMA Coronavirus (COVID-19) Community Update Webinar

July 31, 2020

Thank You For Joining Us Today!

Remember to check out www.curesma.org/covid19 for continuously updated information and resources, and you can always reach us at info@curesma.org.

Cure SMA General Topics

Kenneth Hobby
President

General Overview

- **COVID-19**
 - Higher levels of infections
 - Local variation, but more widespread now than in Spring
 - Hospital systems stressed
- **Staying Safe**
 - Need to continue isolation protocols
 - Longer than general population
 - August and September
 - Potentially beyond
- **Staying Healthy**
 - Treatments and timing are essential
 - Care and trials are important
 - Should have flexibility

New Issues

- **As Isolation Goes Longer...**
 - Economic needs of working
 - Individual and local specific decisions
 - Virtual approaches to:
 - Work
 - School (monitor for first 2 months, siblings)
 - Social and mental health
- **In-Person Events**
 - Going virtual through year-end
 - Summits
 - Socials
- **Repeat and New Resources**

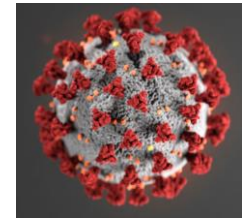
Future Issues

- **Become Controlled or Real 2nd Wave**
 - Combined into flu season
- **Treatments**
 - Shouldn't change approaches for SMA patients
- **Antibody Testing**
 - Not accurate enough to change isolation based on positives
- **Vaccines**
 - Data needed first on efficacy
 - Advocacy for priority access
- **Next Update**
 - End of September/Beginning of October

Cure SMA Medical Discussion

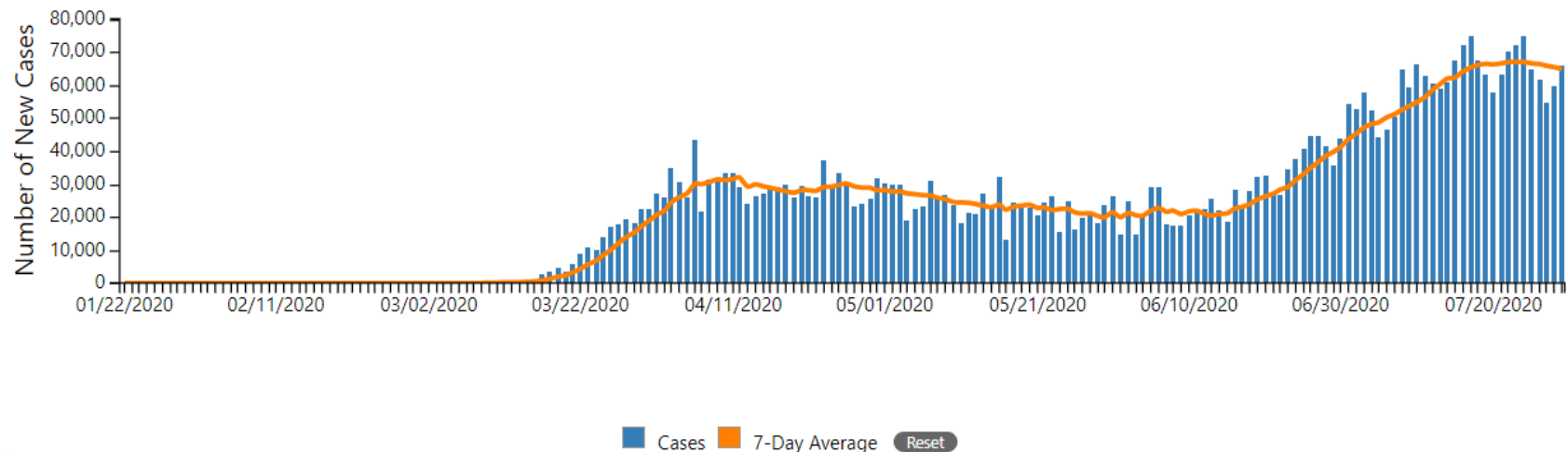
Mary Schroth, M.D., FAAP, FCCP
Chief Medical Officer

COVID-19: Where Are We?



- Continued U.S. spread
- COVID-19 vaccine in early clinical trial; results promising
- COVID-19 antibody testing

New COVID-19 Cases in U.S. Per Day



COVID-19 and SMA

- **Limited Number of People with SMA Have Had COVID-19 Infection**
 - Reported symptoms:
 - Congestion / Increased secretions
 - Fever
 - Loss of or altered taste and smell
 - Not enough experience to generalize
 - Please complete updated COVID-19 survey
 - Email patientcare@curesma.org to share experience

Antibody Testing



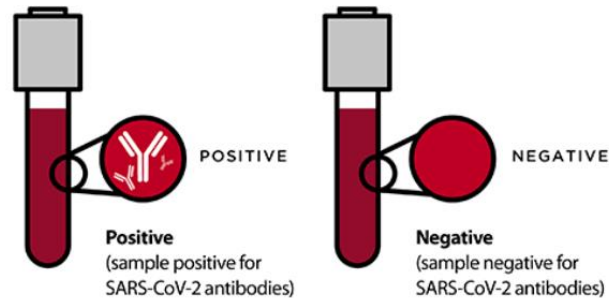
ANTIBODY
AGAINST
SARS-CoV-2

Serology, or **antibody**, testing checks a sample of a person's blood to look for antibodies against SARS-CoV-2, the virus that causes COVID-19. Antibodies usually become detectable in the blood **1-3 weeks** after someone is infected.



*Some people may take longer than 3 weeks to develop antibodies, and some people may not develop antibodies. It is currently unknown how long antibodies are detectable after infection.

A **positive** result from this test may mean that a person was **previously infected** with the virus.



COVID-19 Vaccine Development

- **6 Vaccines In Phase 3 Clinical Trials**
 - Vaccines made from:
 - Coronavirus RNA
 - Coronavirus protein delivered via viral vector
 - Whole inactivated coronavirus
 - Given as intramuscular injection – shot
 - Early testing in people → Increased antibody levels

School Reopening

- **What is Recommend?**
 - Virtual learning for the next 2 months
 - Reassess
- **What Are Schools Doing?**
 - Many school policies and processes to be put in place and tested
 - these mitigate risk, do not eliminate risk
- **Continued Flexibility**

School Reopening Considerations

- **Kids and Spread of Infection**
 - Children <10 seem to become infected and spread infection at a lower rate compared to children 10+ years old and adults
 - *Park et al, Emerg Infect Dis. 2020 Oct. <https://doi.org/10.3201/eid2610.201315>*
- **Children Often Asymptomatic**
- **Schools Want to Keep Staff and Children Safe**
- **Regional Infection Rates**

School Reopening Considerations

- **In-School Practices to Mitigate Risk:**
 - Physical distancing in classroom – ideally 6 feet, new data suggests that 3 feet may be sufficient for children
 - All facing the same direction
 - Wearing masks over nose and mouth and/or face shield
 - Assigned seating
 - Bringing own lunch to be eaten in classroom
 - Cohort or pod of smaller group of children
 - Limited contact with surfaces most people touch (e.g., handles)
 - Ventilation or use of outdoors
 - Plan for someone becoming ill in school

Continue Isolation

- **General Recommendations – Not Changed**
 - Stay at home
 - Wear cloth masks in public – NOSE AND MOUTH
 - Double layer cotton or other thread dense material
 - Physical distancing of at least 6 feet
 - Avoid large gatherings
 - Avoid others who are sick
 - Wash hands often for at least 20 seconds
 - Surface cleaning recommendations continue, are unchanged
 - Possible way to pick up virus but not the most frequent
 - <https://www.cdc.gov/media/releases/2020/s0522-cdc-updates-covid-transmission.html>
 - If COVID-19 exposure, quarantine for 14 days

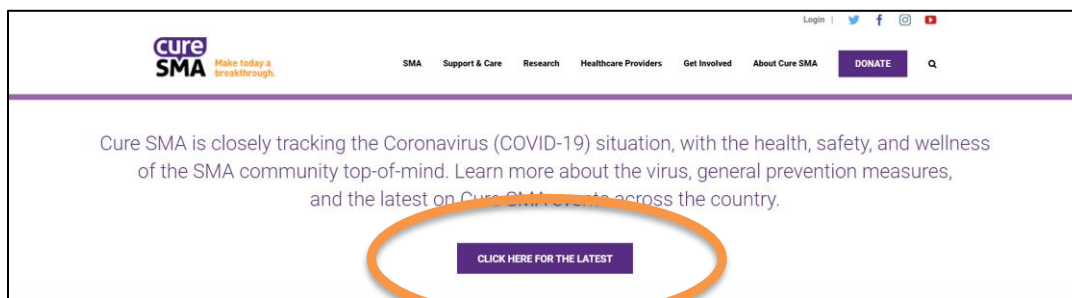
CDC Changes in Home Isolation

- **When to Stop Isolation Following Positive Test**
 - At least 10 days, and 24 hours after last fever without fever-reducing medications, and improved symptoms
 - For severe illness, may need to isolate up to 20 days after symptom onset
 - If no symptoms, can stop isolation 10 days after first positive RT-PCR test

COVID-19 and SMA

- **General Recommendations**
 - Do not delay immunizations – influenza vaccine in September/October
 - Continue to receive SMA treatments
 - No approved medications to prevent infection
 - No approved medications to treat infection at home
 - If hospitalized with severe infection, healthcare team may add remdesivir; if on ventilator also dexamethasone
- **Contact HCP for Specific Questions on Health and testing for COVID-19**
- **Check Local or State Public Health Department Website**

Cure SMA COVID-19 Resources

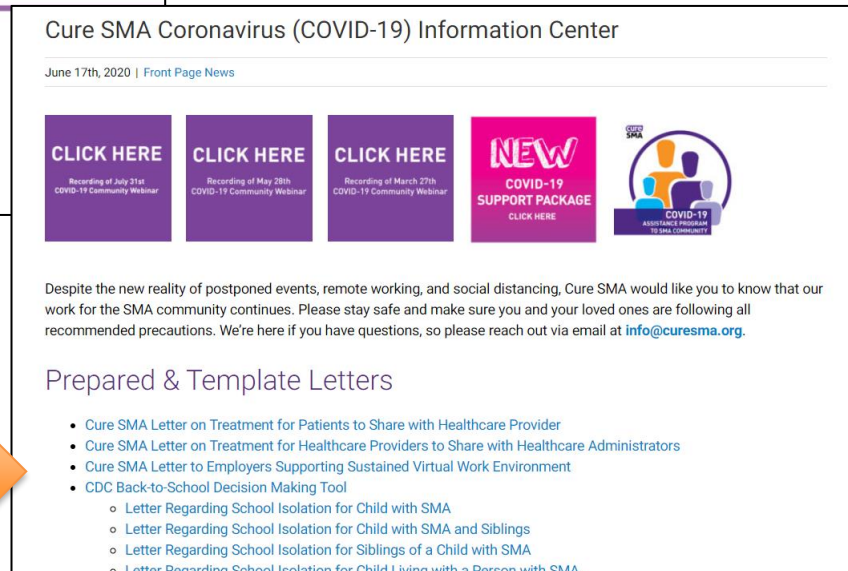


The screenshot shows the Cure SMA website header with the logo and navigation menu. The main content area features a paragraph about COVID-19 tracking and a button labeled "CLICK HERE FOR THE LATEST" which is circled in orange.

Send questions to:
info@curesma.org



Make today
connected.
It's a new world for people with spinal muscular atrophy.



Cure SMA Coronavirus (COVID-19) Information Center
June 17th, 2020 | Front Page News

CLICK HERE
Recording of July 31st
COVID-19 Community Webinar

CLICK HERE
Recording of May 28th
COVID-19 Community Webinar

CLICK HERE
Recording of March 27th
COVID-19 Community Webinar

NEW
COVID-19
SUPPORT PACKAGE
CLICK HERE

COVID-19
ASSISTANCE PROGRAM
FOR SMA COMMUNITY

Despite the new reality of postponed events, remote working, and social distancing, Cure SMA would like you to know that our work for the SMA community continues. Please stay safe and make sure you and your loved ones are following all recommended precautions. We're here if you have questions, so please reach out via email at info@curesma.org.

Prepared & Template Letters

- [Cure SMA Letter on Treatment for Patients to Share with Healthcare Provider](#)
- [Cure SMA Letter on Treatment for Healthcare Providers to Share with Healthcare Administrators](#)
- [Cure SMA Letter to Employers Supporting Sustained Virtual Work Environment](#)
- [CDC Back-to-School Decision Making Tool](#)
 - [Letter Regarding School Isolation for Child with SMA](#)
 - [Letter Regarding School Isolation for Child with SMA and Siblings](#)
 - [Letter Regarding School Isolation for Siblings of a Child with SMA](#)
 - [Letter Regarding School Isolation for Child Living with a Person with SMA](#)

Cure SMA COVID-19 Family Support

**Colleen McCarthy O'Toole
Vice President, Family Support**

Summit of Strength Program

- **In-Person Summit of Strength Programs Cancelled**
 - Cure SMA will be continuing its Summit of Strength Virtual Webinar Series monthly, with new topics starting in August!
 - Events will take place mostly on Wednesdays at 12 p.m. CT
 - **August 12** – Managing the IEP/504 Process During a Pandemic, presented by Kimberly Cook and Tina Lewis
 - **August 19** – Chari-SMA-tic Independence, presented by Angela Wrigglesworth
 - **August 26** – Family Readiness for Emergencies, presented by Dr. Robert Graham

Thank you to the National Presenting Sponsors for the 2020 Summit of Strength Program: AveXis, Biogen, and Genentech. We would also like to recognize Platinum Sponsor, Scholar Rock, for its support.

Virtual Chapter Family Socials

- **Virtual Family Social Program Begins in August!**
 - Individuals with SMA and immediate family members (e.g., parents, siblings, grandparents, spouses, and children) are all invited to join in!
 - Generously Sponsored by AveXis.
 - Email familysupport@curesma.org with any questions.

Virtual Adults with SMA Socials

- **Adults with SMA Virtual Monthly Socials Begin in August!**
 - This virtual Adults with SMA Social is an opportunity for adults with SMA to gather online for 90 minutes in a friendly setting.
 - Through Zoom breakout rooms, attendees will be able to network, catch up with old friends, and meet new friends!
 - Generously sponsored by Biogen.
 - Next social will be on **Tuesday, August 18th, at 7:00 p.m. CT.**
 - Email familysupport@curesma.org with any questions.

COVID-19 Support Package

- **Available Support Program**
 - Launched in April to help individuals and families
 - Available for any SMA household in the U.S.
- **Support Package Includes Essential Items That May Be Difficult to Find at This Time**
 - Items include antibacterial wipes, antibacterial hand sanitizer, tissues, lotion, activity books, and more

For more information and to fill out the application form, please visit <http://events.curesma.org/covidassistance>

COVID-19 Assistance Program

- **New Program That Offers a \$50 Gift Card**
 - Buy essential items such as meals, groceries, or other supplies
 - Available for any SMA household in the U.S.



For more information and to fill out the application form, visit <http://events.curesma.org/covidassistance>

Medical Alert Bracelet Program

- **New Program Sponsored by Genentech**
 - Program offered to all affected individuals with SMA to help identify their medical needs in case of a medical emergency.
 - The comprehensive personal health record package is provided so that medical personnel can immediately access a patient's medical records stored online, whether the patient is able to communicate for themselves or not.
- **Eligibility Criteria:**
 - Must have confirmed SMA diagnosis.
 - Must live within the United States.
- **Link to Apply:**
 - <http://events.curesma.org/responderPHR>



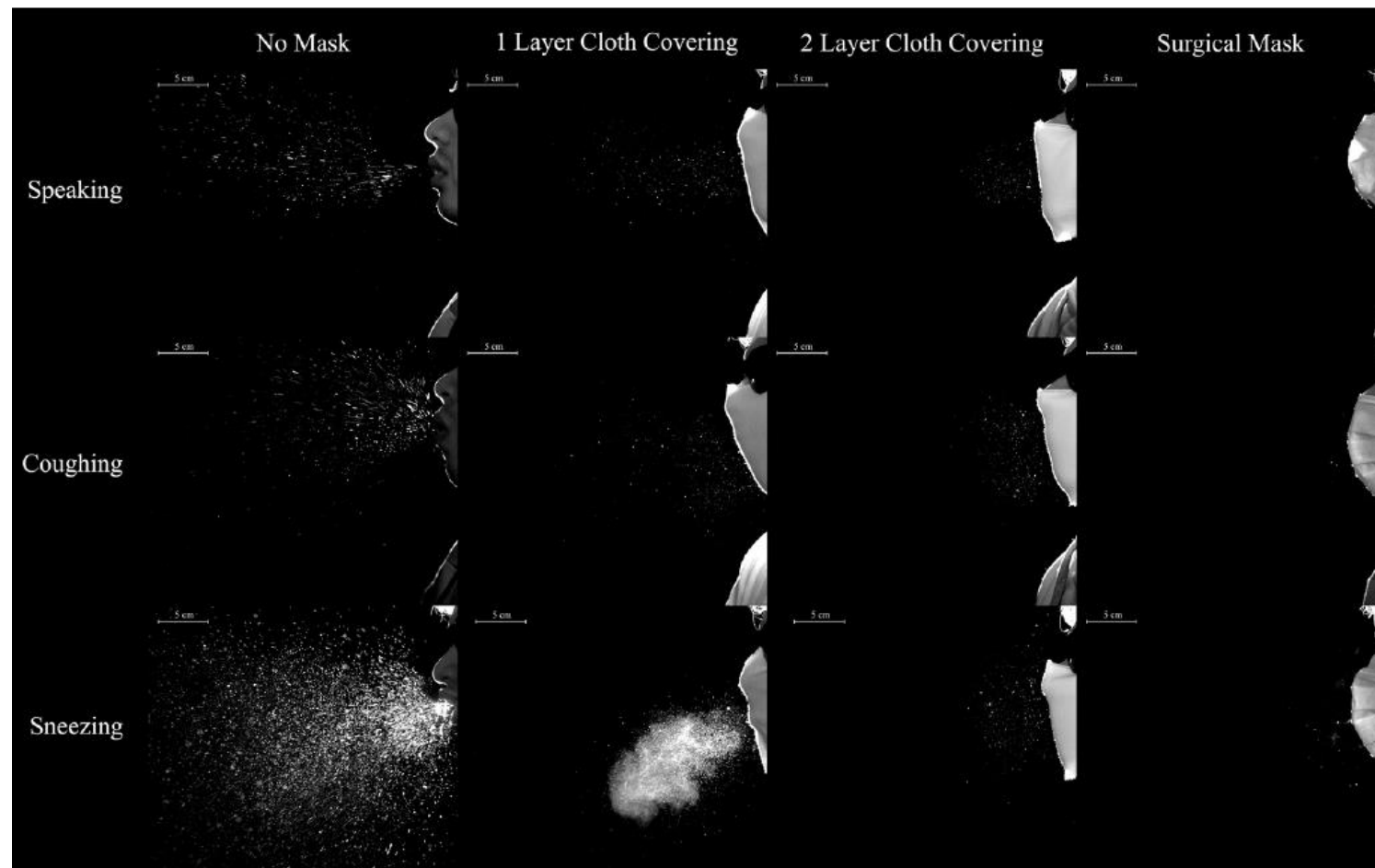
What are your recommendations if somebody in a household were to be diagnosed with COVID-19? How do we isolate somebody with SMA who needs full care (i.e., getting in/out of bed, eating/bathroom needs, etc.)?

Remember to check out www.curesma.org/covid19 for continuously updated information and resources, and you can always reach us at info@curesma.org.

Do you have any best practices for PCA safety protocol? Should they wear a mask the whole shift? Should I wear a mask when near them? Any benefit to them changing clothes/shoes upon arrival to my home?

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Face Coverings and Mask Choices on Droplet Dispersion



Is it safe to take our children into the hospital or a doctor's appointment? They are older SMA kids and are not getting Spinraza?

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Any advice for patients or family caregivers who own their own business and financially cannot afford to close down/stay home? This means having to sometimes to go into public spaces or other people's houses?

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If I must go back to work as a teacher, what should I do each day before coming home to my own kids with SMA? What kind of masks are best?

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I have a child with SMA, and their sibling is starting kindergarten this fall. Should I send them when schools do start opening?

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Thank You and Stay Well!

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