



**Medical and Research Advisory Committee
Sickle Cell Disease Association of America, Inc.**

Recommendations for Coronavirus (COVID-19) Preparedness

**Health Alert for People with Sickle Cell Disease
and their Caregivers**

This document will be updated if more information is available.

April 1, 2020 – COVID-19, the coronavirus disease of 2019 - also known as Coronavirus-2 (also called SARS-CoV-2) - and the illness it causes is on everybody's mind. If you or your family member has sickle cell disease (SCD), you may be worried about what this new disease may mean to you.

The more you learn about COVID-19, the better you can understand what to look for, how to protect yourself or your loved one, and what to do IF you feel sick.

SCDAA and its Medical and Research Advisory Committee want to help you understand COVID-19, how it may affect a person with SCD, and what you can do to help.

The potential health risk posed by COVID-19 for people with SCD is a real concern. The knowledge we have about how COVID-19 will affect those living with SCD is evolving constantly. In light of this, the risks to our community may change in the coming days, weeks and months. **It is critical that you stay regularly informed.**

Members of MARAC have been speaking daily with other experts around the world to get new information that may be useful to you.

What You Need to Know About the Coronavirus (COVID-19)

The coronavirus pandemic is real; it is not just a scare tactic, and it is not fake news.

People who have SCD may have a more difficult time IF they get COVID-19; it is better to protect yourself from getting the infection.

Frequently Asked Questions

What can I do to make sure that I do not get COVID-19?

Stay home as much as possible.

- Do not leave home unless absolutely necessary.
- If you **MUST** go out, remember to do these when you get to where you are going and as soon as you return home:
 - Wash your hands with soap and water for 20 seconds (that is, don't stop until you finish singing the "Alphabet song" once or "Happy Birthday" twice) after you touch anyone or anything outside, as soon as you can; or,
 - Use hand sanitizer with at least 60% alcohol to rub your hands.

What to do if you feel sick:

- **CALL** your doctor, nurse, healthcare team, or hospital immediately.
- Do not just rush to the hospital. **CALL** first, if possible.
- Tell them how you feel.
- Remember to tell them you have SCD.
- Please consider going to the hospital if you continue to feel sick and are unable to reach anyone for advice.
- Be careful when you meet other people. Try to protect yourself and them, as well.
 - Do not get too close to anyone, especially a person who is coughing, or sneezing.
 - Stay farther than you can touch each other by stretching out your arm.
 - Greet one another by waving from a distance (no hugs or handshakes).

Reduce the spread of germs in your house or place of work:

- **Use disinfectants:** Use a disinfectant to clean surfaces (like counter tops, tables, and arms of chairs) or things that were touched by others because a strong disinfectant can kill the virus; and,
- **Keep surfaces clean:** Clean surfaces frequently with a disinfectant if you or other people use or touch the same surfaces or things often. The virus can live on surfaces for many days.
- **Cover your mouth and nose:** Remember to cover your mouth and nose with a tissue when you cough or sneeze.
 - Then immediately wash your hands.
 - If you do not have tissue, cough or sneeze into your clothes. Do not cough or sneeze into your bare hands or skin.
- **Protect parts of your face:** Do not touch your eyes, nose, mouth, or face; the virus can get into your body through those body parts.
- **Stay away from anyone in your home that is sick:** Those positive for COVID-19 or think they may have it should follow the advice at the CDC website (<https://www.cdc.gov/coronavirus/2019-ncov/if-you-are-sick/steps-when-sick.html>)
- **Masks:** They are not enough to protect you from the COVID-19 infection:
 - There are many different opinions about whether you should wear a mask, but if you are using a mask please follow these guidelines:
 - They can be reused but should be replaced when visibly soiled or damaged.
 - They should be stored in a clean paper bag between uses.
 - When storing, fold the mask so that the inner surface is held against itself to reduce contact with the outer surface.

How can I get myself and my family prepared?

Use this checklist if it helps you to prepare.

- _____ **Refills:** Please check to see if you have refilled all your medications so that you do not run out.
- _____ **Extra medications:** Contact your doctor, nurse or hospital to ask about getting extra medications to have on hand in case there is an outbreak of COVID-19 in your community and you need to stay home for a long time. Some pharmacies are offering home delivery.
- _____ **Over the counter medicines and supplies:** Be sure you have over-the-counter medicines and medical supplies (e.g. tissues).
- _____ **Thermometer:** Make sure you have a thermometer to take your temperature and clean it after each use.
- _____ **Take your prescribed medications for SCD:** hydroxyurea, glutamine, penicillin, folic acid, Voxelotor, Crizanlizumab, Deferasirox, and any others. These medications will help keep your body in the best possible condition to fight off infection.
- _____ **Pain medications:** Make sure you have enough of your pain medications and use them when you have regular sickle cell pain.

In addition, plan for any of the following that apply:

- _____ **Household items and groceries:** Have enough household items and groceries on hand so that you will be prepared to stay at home for a period of time that could be many weeks.
- _____ **Ways to stay in touch:** Stay in touch with others by phone, text or email. You may need to ask for help from friends, family, neighbors, etc. if you become ill.
- _____ **Ways to keep children occupied:** Keep children occupied with home school activities, arts and crafts.
- _____ **Caretakers for loved ones and pets:** Think ahead about who will watch your children, other loved ones, or pets if you become too sick.
- _____ **Working from home:** Find out if working from home is an option.

How do I know if I have COVID-19?

The only way to know for sure that you have coronavirus is to get tested. However, it is not easy to get tested yet as many places have limited access to testing kits. We hope that this will change soon. In low resource countries, there are even fewer places to be tested. Your sample may need to be sent to a lab far from where you are. Your health care team will arrange for your test to be done.

Most people who have COVID-19 have the following symptoms:

- Fever
- Cough
- Shortness of breath

NOTE: These together can be a sign of Acute Chest Syndrome of SCD, as well as the serious pneumonia seen in COVID-19. This would be the major concern of COVID-19 in a person with SCD.

****Some people who have COVID-19 have diarrhea and/or a change or loss of smell or taste.**

If you have any of the above symptoms:

Call your doctor, nurse or hospital right away to discuss what you should do next.

In addition, you or someone should call for emergency help, (911 in the US), if you have:

- Difficulty breathing
- Pain or pressure in the chest different from your usual sickle cell pain
- New confusion or inability to wake up easily
- Darker lips or face than usual

What should I do if I have a fever?

- Call your sickle cell doctor, primary care physician, nurse, or hospital to report your illness and arrange to be checked.
- Do NOT immediately rush to the emergency department.
- It is not a good idea to stay at home to “wait and see” and just take medications to force down your high body temperature.
- Be aware that lots of different things can cause fever, such as infections and sickle cell tissue damage. Fever does not mean you have coronavirus!

What are some good ways to stay as healthy as possible?

- Take your medications as prescribed.
- Drink plenty of fluids, as usual.
- Try to rest and not do too much physical activity.

Should I continue getting my chronic transfusions?

- Regular transfusions are given often to prevent serious complications like stroke.
- Continue your regular transfusions unless your healthcare team tells you to stop.
- Blood supply may be short so your doctor may need to change the transfusion plan.
- Blood transfusion is still safe; COVID-19 has not been passed through transfusion.
- Talk to your healthcare team if you have concerns about blood and COVID-19.

What if I don't have a doctor?

- Many hospitals are setting up ways for patients to have a visit with a healthcare provider over the telephone. These are called "e-visits" or "telemedicine".
- Many communities have hotlines available for people to call for help and advice.
- If you are unsure, you can always call your local SCDAA chapter for advice on resources in your community.

Should I go to the emergency department if I am ill?

- If you have a doctor, nurse, or health care team, it is recommended that you call for advice, if you can, before going to the emergency department.
- Emergency departments are very full of sick people right now and it is likely that there will be long waits.
- Also, it is very likely that people with COVID-19 infection will be there.
- If you have no other option, then going to the emergency department may be the only option.
- Try and call ahead to see if they have recommendations beforehand.

I think I am having sickle cell pain. What should I do?

- **If your pain feels different or is not responding to your usual home treatment, or you also have fever, cough or trouble breathing, call your healthcare team for advice and arrange to be checked.**
- Otherwise, try to manage your sickle cell pain at home in order to avoid a busy emergency department or medical center that may have people with COVID-19 seeking care.

Is it safe to travel?

- It is best to avoid all travel at this time unless there is some emergency.
- If you must travel, talk to your healthcare team or visit the website of the Centers for Disease Control and Prevention (CDC) for travel guidance (www.cdc.gov/covid19) to stay up to date.

What do I do if I am on a research study?

- It is important that you get in touch with your research team right away to check if there are any changes. And, thank you for being on a clinical trial.

I feel fine so far. Is there anything I can do to help others?

- If you know others living with SCD, contact them by phone, text or social media. Make sure they are doing “ok” and see if they need help or reassurance. It is a stressful time for a lot of us. If you know people who are willing to donate blood, encourage them.

Will there be a shortage of blood soon?

- This is very possible, but you can help! If there are people in your family or community that are willing to donate blood, please encourage them to call the local blood bank right away. During times like these, there can be a lot of blood shortages and we know that many people with SCD (as well as other conditions) need blood. See if you can get some people to donate. People with sickle cell trait are still able to donate so please encourage them to do so.

How do I stay informed?

- (1) Go to www.OneSCDVoice.com, SCDAAs online information superhighway where we will post updates regularly that are specific to SCD. It is free to join.
- (2) Go to the website of your local SCDAAs organization. You can find the one closest to you at www.sicklecelldisease.org. There may be some useful information that applies directly to your community.
- (3) Go to the **CDC's website** (www.cdc.gov/covid19) for regular updates on the COVID-19. Information is updated routinely and will keep you abreast of the latest guidelines and recommendations. There is information on how you can start to prepare in your homes and community.

For More Information, contact info@sicklecelldisease.org



Additional Resources

This website has tips for families including ways to promote coping broken down by age group: https://www.nctsn.org/sites/default/files/resources/fact-sheet/outbreak_factsheet_1.pdf

This website has resources for anxiety and your mental health in a global climate of uncertainty.
<https://www.virusanxiety.com/>
<https://www.virusanxiety.com/>

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