



## Medical and Research Advisory Committee Sickle Cell Disease Association of America

### Recommendations for Coronavirus (COVID-19) Preparedness

## Health Alert for Patients and Caregivers

**March 17, 2020** - With COVID-19 on the forefront of nearly everyone's minds, the Medical and Research Advisory Committee (MARAC) at SCDAAs wants to provide information to our sickle cell community. Educating yourself about the coronavirus reduces anxiety and empowers you to protect yourself – and your family – from getting sick. **The potential health risk posed by COVID-19 is a real concern.** The knowledge we have about how COVID-19 will affect those living with sickle cell disease is evolving constantly. In light of this, the risks to our community here in the United States may change in the upcoming days, weeks and months. **It is critical that you stay regularly informed.**

MARAC is in constant communication with health authorities across the globe as well as international sickle cell specialists who are taking care of individuals living with sickle cell disease. We will continue with regular updates for the community based on evidence and detailed accounts of the impact in countries who have struggled longer than we have.

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

**The pandemic is real.** This is **not** an exaggeration of the facts. This is **not** “fake news”. We are all at risk of getting infected. Individuals with sickle cell disease have weaker immune systems than most other people. The best way to prevent serious illness is to keep from getting infected in the first place.

## Frequently Asked Questions

### What can I do to prevent the spread of COVID-19?

Here are some tips:

- Stay home as much as possible. Do not leave home unless absolutely necessary.
- Wash your hands with soap and water for 20 seconds (don't stop until you finish singing the "Alphabet song") or use hand sanitizer with at least 60% alcohol.
- Avoid touching your eyes, nose, mouth, and face.
- If you feel sick, call your medical provider immediately.
- Avoid being close to people who are visibly sick, coughing, or sneezing.
- Greet one another from a distance (no hugs or handshakes).
- Disinfect frequently touched objects and surfaces. The virus can live on these surfaces and get transmitted this way.
- Cover your cough or sneeze with a tissue you can discard, then immediately wash your hands.

### How can I get myself and my family prepared?

- Please check to see if you have refilled all your (your child's) medication and are not about to run out.
- Contact your (your child's) doctor 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 period of time. Some pharmacies are offering home delivery.
- Be sure you have over-the-counter medicines and medical supplies (e.g. tissues) to treat fever (e.g. Tylenol) and other symptoms.
- Make sure you have a thermometer to take your temperature.
- Take your prescribed medications for sickle cell disease (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.
- 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.
- Stay in touch with others by phone or email. You may need to ask for help from friends, family, neighbors, etc. if you become ill.
- Think ahead about who will watch your children, other loved ones, or pets if you become too sick.
- 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 all 50 states have limited access to testing kits. We hope that this will change soon.

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

- Fever
- Cough
- Shortness of breath

If you have any of these symptoms, call your doctor right away to discuss what you should do next.

Call 911 if you have:

- A lot of difficulty breathing
- Unusual persistent pain or pressure in the chest
- New confusion or inability to wake up easily
- Bluish lips or face

## What should I do if I have a fever?

Do not immediately rush to the emergency department. You should call your doctor right away if you have a fever and you should use a thermometer to be sure you really do first. This is key. Lots of different infections can cause a fever. This does not automatically mean you have COVID-19. Call your doctor first and find out where to go. They will ask about other symptoms too.

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

- Take your medications as prescribed
- Stay hydrated
- Try to get good rest

## Should I continue getting my chronic transfusions?

Continue all of your treatments until you talk it over with your doctor. There is no evidence right now that COVID-19 is transmitted through blood but there is a lot we still do not know. Balancing the need for transfusions to reduce things like stroke must be taken into consideration when making this decision. If you have concerns with going in for your transfusion, you should ask your doctor about any risks of missing a transfusion. If there is a shortage of blood supply in your region, ask your provider if there is any alternative. Bottom line is talk to your doctor.

### **What do I do if I don't have a doctor?**

Many of our healthcare centers are setting up ways for patients to have a visit with a healthcare provider over the telephone. These are called “e-visits” or sometimes referred to as “telemedicine”. Many states and local communities have hotlines available for people to call for help and advice. If you are unsure, you can always call your local SCDA chapter for advice on resources in your community.

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

If you have a doctor, it is recommended that you call for advice if you can before going to the emergency department. Emergency departments are very full right now and it is likely that there will be long waits. Also, it is very likely that infected people will be there. If you have no other option, then going to the emergency department is the best option, but please use your other options first.

### **I think I am having a pain crisis episode. What should I do?**

Carefully weigh your options and call your doctor to get advice on what to do. Consider the benefit of managing pain at home versus the risk of getting exposed to someone with COVID-19 in the clinic, emergency department or hospital. If it feels like a typical pain crisis episode for you, they may suggest you try to do everything you can to manage your pain at home. If you are comfortable trying to manage at home, ask your doctor to call in prescriptions for pain medications. If you have symptoms of COVID-19, you should alert your doctor and say, “This feels different from my usual pain crisis” and ask what you should do next. Make sure you have checked your temperature because you will be asked if you did.

### **Is it safe to travel?**

It is best to avoid all non-emergent travel at this time. If you must travel, visit the CDC's website for travel guidance ([www.cdc.gov/covid19](http://www.cdc.gov/covid19)) to stay up to date.

### **Have any individuals with sickle cell disease been diagnosed with COVID-19?**

Yes, we are aware that some have. We are not aware of any deaths among those living with sickle cell disease. This could change.

### **What do I do if I am on a clinical trial?**

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

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

If you know others living with sickle cell disease, 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 sickle cell disease (as well as other conditions) need blood. See if you can get some people to donate.

## How do I stay informed?

- (1) Go to [www.OneSCDVoice.com](http://www.OneSCDVoice.com), SCDA's online information superhighway where we will post updates regularly that are specific to sickle cell disease. It is free to join. We are not aware of any other more trusted resource specifically for individuals with sickle cell disease.
- (2) Go to the [CDC's website \(www.cdc.gov/covid19\)](http://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.

## Definitions

Pandemic - A worldwide outbreak of a disease

**For More Information, contact [info@sicklecelldisease.org](mailto:info@sicklecelldisease.org)**



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