



COVID-19 Weekly Bulletin #10

Monday, June 1st

We are extending our support by sharing resources through the Sick Cells' Weekly Bulletin to educate and empower the community during this unprecedented time. **#SCDSticksTogether**

Message from Sick Cells

For the last few months, our community has disproportionately suffered physically, financially and otherwise from COVID-19. Now, recent events of racial injustice, ignited by the death of Mr. George Floyd, weigh heavily on the nation, and in particular, on Black and Brown communities. Systemic racism has been a public-health crisis for much longer than the current pandemic, and has exacerbated the health disparities for people with sickle cell disease.

During these challenging times, we are continuing our work to improve the lives of people with sickle cell disease. Please continue to take care of yourself, your family, and your community. If you are participating in the protests, please take the following precautions to mitigate the spread of the coronavirus:

1. Wear a mask and eye protection.
2. Bring hand sanitizer and practice proper hand hygiene.
3. Keep social distance and avoid vulnerable populations after any potential exposures.
4. Stay hydrated.

SCDAA Health Updates

Follow [SCDAA's Health Alerts](#) to stay regularly informed about COVID-19 and what you need to know as SCD patients and caregivers. The SCDAA medical advisory committee is in constant communication with health authorities and will continue to provide updated recommendations for COVID-19 preparedness. For the provider advisory, click [here](#).

COVID-19 Updates

This section provides the latest information to provide an overview of the outbreak.

- States are reopening bit by bit. This means that more public spaces are available for use and more and more businesses are being allowed to open again. The federal government is largely leaving the decision up to states, and some state leaders are leaving the decision up to local authorities. **It is important to [continue monitoring the outbreak](#) in your local areas.**
- **What does reopening mean for our sickle cell patients?** SCDAA's Medical and Research Advisory Committee issued guidance for economic reopening. Read their recommendations [here](#).
- People with [sickle cell disease are considered a "vulnerable" population](#) during the reopening of the U.S. economy and **need to remain at home as much as possible.**
 - If you are considered part of a vulnerable population, **continue to stay at home except for essential trips.**



- It's still a good idea to **limit your interaction with other people**.
- Patients with sickle cell disease should **continue to work from home as much as possible**.
- The CDC reports that the virus is [mainly spread from person-to-person](#). The best way to prevent illness is to avoid being exposed to this virus:
 - Avoid close contact with another person (distance should be greater than 6 feet away)
 - Limit spread of respiratory droplets (produced when an infected person coughs, sneezes or talks) by wearing a face mask
 - Wash your hands often
 - Clean and disinfect frequently touched surfaces daily
- The [SECURE-SCD Registry](#) is designed to capture pediatric and adult COVID-19 cases that are occurring across the world in patients living with sickle cell disease. Providers caring for these patients are asked to report all cases to this registry. You can review [updated summary information and data](#) from the registry.
- The American Red Cross needs the help of blood and platelet donors and blood drive hosts to ensure the health of our communities. Learn more about [COVID-19 and blood donations](#) on their website.

Policy Updates

This section highlights executive orders and legislation in response to the COVID-19 crisis.

- **Supplemental Nutrition Assistance Program (SNAP)** participants will be able to select and pay for their groceries online. Currently, [the SNAP online purchasing pilot](#) is operational in 28 states and the District of Columbia, with additional states going live each week.
 - To determine if **grocery delivery** is available for your location, you can visit the retailer websites listed for your state.
- The **Paycheck Protection Program (PPP)** is still underway. If you are a small organization, you can [submit your application](#) today.
- To receive **unemployment benefits**, you need to file a claim with the unemployment program in the state where you worked. [Here's how to get started](#) applying for unemployment benefits in your state.
- [Here are some key things](#) you may need to know about how **student loans** are impacted by the CARES Act.

Sickle Cell Disease Emergency Funds

In this section, we highlight relief funds that may be available to support the community.

- The Sickle Cell Consortium launched the **Sickle Cell Patient & Family COVID-19 Relief Fund**. This is open to sickle cell families that have been impacted by the pandemic. For more information please visit: <http://sicklecellconsortium.org/covid19>
- **NORD launched a Financial Assistance Program for rare disease community members impacted by COVID-19**. Through [the new program](#), NORD will provide



financial assistance to eligible patients, covering up to \$1,000 annually. To apply, email COVID19assistance@rarediseases.org.

- **HealthWell has launched a new fund to provide copayment and premium assistance to support the sickle cell community.** Through the fund, HealthWell will provide up to \$10,000 in financial assistance for a 12-month grant period to eligible patients who have annual household incomes up to 500 percent of the federal poverty level. For more information visit HealthWell's [Sickle Cell Disease Fund](#) page.
- **The Sickle Cell Disease Association of America (SCDAA) launched a COVID-19 Emergency Fund** to assist sickle cell non-profit organizations in helping their community members with health care, food insecurity, and other related concerns. Visit the [SCDAA website](#) to learn more.

Wellness Resources

Mental stress and trauma can trigger episodes of pain crisis in people with sickle cell disease. This week, we are reinforcing strategies that can help manage stress levels and avoid potential crisis triggers. We've utilized the "[Managing Stress and SCD Crisis](#)" article as a resource.

- **Sleeping more:** Getting too little sleep can add to the stress you already feel. Here are some [healthy sleep tips](#) to ensure you receive adequate sleep.
- **Doing more physical activity:** Physical activity triggers the release of endorphins that are known to influence more positive moods. You can utilize [the WHO web page](#) for encouragement and ideas to participate in their campaign to be #HealthyAtHome.
- **Talking to someone:** It is important to have a good support system. [Be The Match](#) is now offering **free counseling services** to sickle cell warriors and their loved ones. One of their licensed social workers can provide you with one-on-one support for personal and emotional issues.

How are you coping during these challenging times? Tag us on socials so we can see!
#SCDSticksTogether #WeeklyBulletin