

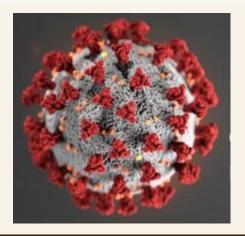
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SPRING 2020 NEWS

This has already been a year for the history books, but SCDAA-MI is providing you with news and information to help get through today. In this edition: Reach out through our COVID-19 needs assessment, learn about our SAFER emergency room initiative, let us help you find a physician, and it's time to get ready to walk. Read on!

Visit our new website with special sections for Patient Support, COVID-19 resources, and Sickle Cell 911. You can even leave us a testimonial. www.scdaami.org

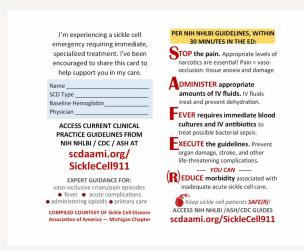
Is the COVID-19 pandemic stretching your resources? Reach out!

COVID-19 has placed immense strain on Michigan's resources and, especially, on many of the individuals we serve. The SCDAA-MI would like to know how you're doing during this unprecedented time. We'd like to hear from those of you who need additional assistance right now – or if you know someone with sickle cell who could use our help. To do this, we need to gather information to help us determine how we can best allocate our limited direct resources and to connect patients to other needed services. If you're interested, please complete this 5-minute survey covering mental/emotional, financial, medical and educational needs before midnight April 24, 2020.

SURVEY DISCLAIMER: This survey is voluntary, and will be used to assist the SCDAA-MI with identifying any unmet needs our clients

may be experiencing during this COVID-19 crisis. Your personal information (name, phone number, address, birthdate, etc.) will not be shared with any outside source, and it will not be misused or made public.

SAFER launches to help sickle cell patients receive proper ER care



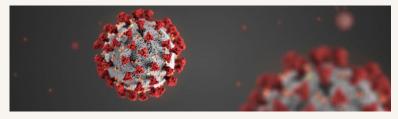
SCDAA-MI launched a new initiative designed to help advance the care and well-being of individuals living with sickle cell disease. The initiative, known as SAFE(R), provides medical professionals with quick access to an online portal at SCDAAMI.org/SickleCell911 that provides clinical practice guidelines for sickle cell established by the National Institutes of Health, sickle cell-specific opioid guidance from the Centers for Disease Control, as well as best practices and recommendations from the American Society of Hematology and other leading experts in sickle cell treatment.

Central to the SAFE(R) Initiative is the wallet-sized Sickle Cell 911/SAFER card, which directs

providers to the SAFE(R) site at **SCDAAMI.org/SickleCell911**. In addition to guidelines, recommendations and best practices, the medical professional-focused pages also provide educational resources about the disease and its potential complications.

Sickle cell patients are advised to carry the SAFER card with them and present it when they need emergency care – whether at home or away. Patients and caregivers have shared stories about ED providers resorting to the internet or medical journals to find information about treating the disease. The SAFE(R) initiative puts that information at providers' fingertips in an easily accessible and usable format, hopefully saving crucial acute care time that in turn leads to saving lives.

SCDAA-MI is here to provide accurate information about COVID-19



We know there's a lot of information floating around about coronavirus/COVID-19 right now. While you're staying at home, sanitizing, stocking up, trying to manage your anxiety, handling any every day pain - and now - probably worried about catching the virus, too, we're here to help:

- **1) Looking for info?** Visit **scdaami.org/coronavirus**. You'll find links to sickle cell care guidance from SCDAA, unemployment info, food resources, current statistics, and more.
- **2) Download your SAFER card**, patient recommendations and provider guidelines at **scdaami.org/patient-support**. These tools and resources give you and your medical providers specific guidance on protecting yourself from the virus and treatment if you get sick.
- **3)** Have you tested positive for COVID-19? Or do you have a cough with a fever? MICHIGAN WARRIORS ONLY PLEASE: You can call Dr. Z (Dr. Ahmar Zaidi) at 248-797-9936 or Dr. Mike (Dr. Mike Callaghan) at 248-953-5250 for assistance. Please respect the docs' time and dedication and only reach out to them if you're diagnosed with Coronavirus or have a cough + fever. We appreciate them being available to the community this way.

For assistance with getting health insurance, a primary care physician (PCP), hematologist, or help navigating any other services:

Email us at info@scdaami.org or call:

Detroit/Southeast Michigan 313-864-4406 or 800-842-0973

Caseworker at the DMC adult clinic: (313) 613 7327

Jackson/Lansing Area: (517) 394-7397 Saginaw/Flint Area: (989) 755-7752

Benton Harbor/Kalamazoo Area: (269) 927-5629 Grand Rapids/Muskegon Area: (616) 243-1868 IMPORTANT: Warriors outside of Michigan can still access and use the info provided at scdaamiorg/patient-support. Those resources are created for all individuals with sickle cell. However, we encourage you to contact your local community-based sickle cell organization for location-specific information on services, etc. You'll find a listing here.

Follow the docs on Twitter: Dr. Shurney @ whittenshurney, Dr. Z @ drzsicklecell and Dr. Mike @ hemagineer.



It's time to get ready for the 2020 Sickle Cell Matters Walk!

Registration for our 2020 Sickle Cell Matters Walk is open at www.scdaami.org/2020walk.

Join us Saturday, Sept. 19, 2020 at the Charles H. Wright Museum of African American History from 9 a.m. – noon. Our 2020 Walk features a special Warriors-only performance, a salute to our Legacy Warriors (ages 50 and up), voter registration, and all the prizes, giveaways and fun you've come to expect plus more.

Times are uncertain, but one thing's for sure: The need to keep our cause in front of the world has never been greater. COVID-19 has brought new attention to medical inequity. We'll stay on the front lines today and in the future. **Register now.** #togetherapart #sicklecellmatterswalk

IMPORTANT CLINIC NEWS:

The adult sickle cell clinic at DMC has reduced its hours in response to the COVID-19 pandemic.

Current hours are Mondays and Wednesdays ONLY, from 8:30 a.m. – 4:30 p.m. Patients will need to call (313) 745-2554 and leave a message to schedule an appointment. Someone will call you back. E-scripts and telemedicine aren't available at the clinic yet, and refills will only be provided to patients who are seen. (Testing will still be required.) So, if you need an immediate medication refill, please contact your primary care physician or hematologist.

IF YOU DO NOT HAVE A PRIMARY CARE PHYSICIAN NOW IS THE TIME TO GET ONE! Not only should you have a PCP for your routine healthcare, you'll need one in order to access COVID-19 testing should you need it. For a list of Detroit area medical offices and providers currently accepting new patients (insured and uninsured), click here.

If you have questions or need additional assistance securing insurance and/or a PCP, please contact our caseworker at the adult clinic at (313) 613 7327.



Do you need a doctor?

The City of Detroit and the Coronavirus Community Care Network want to ensure all residents have access to testing. **Click here** for a list of doctors accepting new patients today in the City of Detroit.

SUMMER CAMP HAS BEEN CANCELLED

(Click image to read the full notice)

The benefits of Vitamin D



<u>Vitamin D</u> is a <u>nutrient</u> found in some foods that is needed for health and to maintain strong bones. It does so by helping the body <u>absorb calcium</u> (one of bone's main



Healthier eating tips from the American Heart Association



We're sharing suggestions for healthier staples to stock up with while sheltering in place. **Learn more.**

HAVE YOU TAKEN THE 2020 CENSUS?



Data gathered from the 2020 Census will help inform funding decisions for school lunches, infrastructure, first responders and more. Your answers are confidential and there are no citizenship questions. Take 10 minutes to answer the census today.

building blocks) from food and <u>supplements</u>. People who get too little vitamin D may develop soft, thin, and brittle bones, a condition known as <u>rickets</u> in children and <u>osteomalacia</u> in adults.

Vitamin D is important to the body in many other ways as well. Muscles need it to move, for example, <u>nerves</u> need it to carry messages between the brain and every body part, and the <u>immune system</u> needs vitamin D to fight off invading <u>bacteria</u> and <u>viruses</u>. Together with <u>calcium</u>, vitamin D also helps protect older adults from <u>osteoporosis</u>. Vitamin D is found in <u>cells</u> throughout the body." (Source: National Institutes of Health Office of Dietary Supplements)

Thank you to our recent donors and everyone's who's hosted a Facebook fundraiser for us.

Recent funders:

Global Blood Therapeutics Sickle Cell Disease Association of America

Recent donors:

Zhi Li Alexus Lollie

Facebook Fundraisers:

LeAnne Banks
Faith Barkley
Randi Cathey
Stephanie Crider
Versetta Brown Eaddy
Michelle Slater
Mike Young

You can host a Facebook fundraiser for us, too. Click here for the easy instructions. Your donations help with education, outreach and advocacy. Every dollar counts in this quest to cure sickle cell.



LEARN MORE

Podcasts

Cheat Codes: A Sickle Cell Podcast

Sickle Cell 101

Online Sickle Cell Communities

oneSCDvoice was created with the vision of empowering those impacted by sickle cell disease through facilitating access to information and support from the sickle cell disease community.

Generation S is encouraging those who live with sickle cell disease to share their experiences. Together, we're turning the page on the silence surrounding sickle cell disease.

FOLLOW US







