



It's a new day, it's a new year, and our sights are set on a brighter future for sickle cell! Welcome 2020!

Inside our January newsletter is a chance for individuals with sickle cell and caregivers to speak out and help influence the price and availability of new disease treatments. Further down, you'll see details on our Feb. 29 treatment workshop, an article on the origins of sickle cell, and tips on meditation to help maintain your peace of mind. Last but not least, save the date for our 2020 Sickle Cell Matters Walk on Sept. 19. Read on!

What's it like to live with sickle cell?

It's time to be heard!

A **short survey** from SickCells for sickle cell disease patients and caregivers is available until this Friday, Jan. 31 and it's a great opportunity to share your experience.

The survey takes about 15-20 minutes and has been developed by Sick Cells in collaboration with ICER. What's ICER? A private organization that helps influence drug pricing and access. The voices in our sickle cell community need to be louder than ICER's! Your responses are anonymous and will help shed more light on living with SCD day to day, what it's like to be a caregiver, and how much SCD is costing you out-of-pocket.

Fill out the survey before this Friday, Jan. 31. The survey can be taken on a smartphone, tablet, or computer. Share this post or share the link (<https://www.surveymonkey.com/r/mylifewithSCD>), but don't forward from your survey.



WHY IS THIS #SCDSURVEY IMPORTANT?

Reality: There are many out-of-pocket costs of SCD that aren't acknowledged

With your input, we can better understand the true "price tag" of sickle cell disease.

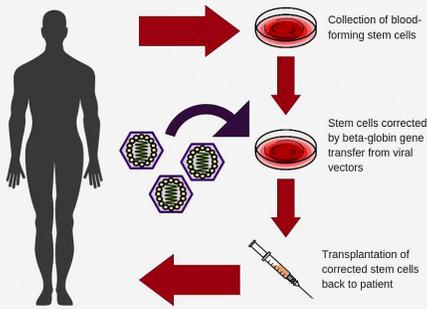
#MyLifeWithSCD #SCDSurvey #ICERSurvey

VISIT OUR WEBSITE

Join us for "Options Up Close: Current Treatments for Sickle Cell," Feb. 29, 11 a.m. - 3 p.m.

Saturday, Feb. 29 from 11 a.m. – 3 p.m.
SCDAA-MI, Education Wing
18516 James Couzens Fwy, Detroit, MI 48235
Bring your questions and experience to a workshop focused on exploring the current options available to treat sickle cell disease. We'll discuss those currently in use as well as the newly FDA-approved Adakveo and Oxbryta, how they work, pros and cons, and accessing care. The event will also be broadcast via Facebook Live. Lunch will be served. Seating is limited. Reserve

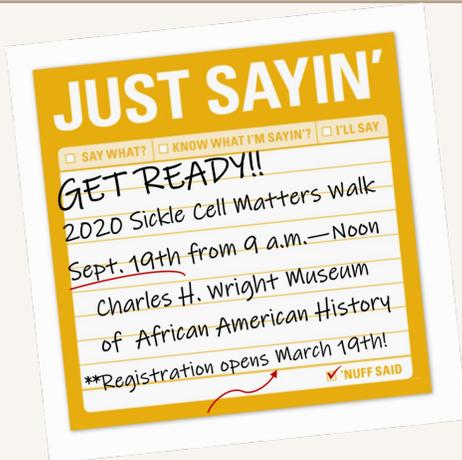
Gene therapy for sickle cell disease



your space today.

For additional information and to RSVP, visit

<https://currenttreatmentsforsicklecell.eventbrite.com>.



2020 SICKLE CELL MATTERS WALK, SEPT. 19 AT THE WRIGHT

Registration for our 2020 Sickle Cell Matters Walk opens March 19 at www.scdami.org.

This year's event takes place Saturday, Sept. 19, 2020 at the Charles H. Wright Museum of African American History from 9 a.m. – noon. Deborah Smith Pollard, SCDA-MI Board Member and Co-host of "Sunday Morning Inspiration" on MIX 92.3 FM, is this year's Honorary Chair. Serving as Honorary Co-Chair is our own "Dr. Z," Ahmar Zaidi, pediatric oncologist/ hematologist at the Comprehensive Sickle Cell Clinic at Children's Hospital of Michigan.

Our 2020 Walk features a special Warriors-only performance, crowning of our 2020 Junior Ambassadors, a salute to our Legacy Warriors (ages 50 and up), voter registration, and more. **Watch your inbox and our website for details coming soon!**

SENATE BILL 612 - PREAUTHORIZATION

We're on it! SCDA-MI staff and sickle cell advocates are traveling to Lansing, MI on January as part of the Health Can't Wait Coalition in support of SB612. The bill will help reduce red tape around preauthorizations and step requirements for medication.

Contact your state senator today and ask them to support the bill. Don't know who your legislators are? Just [click here](#) and fill in your address to find all your elected officials in one place.

ARTICLE: How One Child's Sickle Cell Mutation Helped Protect the World From Malaria - The New York Times

Blood cell artwork copyright The New York Times



Thank you to everybody who contributed to



MIND CARE: Seven Different Types of Meditation

From transcendental to metta, find out how different forms of meditation can help you relax and manage stress.

Tips from everydayhealth.com are provided as a courtesy and should not be construed as medical advice. If you feel you are in need of specialized care for your mental health, please contact your physician or call us at 313-864-4406 for personal assistance. For help with a mental health crisis, call 1-800-273-TALK (8255).

our Giving Tuesday fundraiser on Facebook – and to everybody who gave one on for us! You can host a 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.

#thankyou!

Questions about anything in this newsletter? Contact us at info@scdaami.org

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

