

Shine the Light on Sickle Cell Disease

**World Sickle Cell Awareness Day
June 19, 2020**



Community Gathering Guide

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In celebration of **World Sickle Cell Awareness Day** – join us on **June 19, 2020** to:

Shine the Light on Sickle Cell Disease

Together, we – you, your friends, family, neighbors and others in communities across the nation and around the world – will have the opportunity to stand up, speak out, and **Shine the Light on June 19** to ...

- Increase awareness
- Build support networks
- Raise critical resources, and
- Strengthen our collective resolve to

... advocate for access to services and a universal cure for sickle cell disease.

If you are interested in hosting a **Shine the Light** gathering in your community ... you will find some ideas and tips in this **Community Gathering Guide** to help you get started and have a successful event ... or if you just want to attend a gathering hosted by others, you can find out where one is being held near you by either:

- Checking out events posted on the Shine the Light Facebook page: www.facebook.com/ShineTheLightOnSickleCell ... or by
- Sending us an email: ShineTheLightOnSickleCell@gmail.com

Hosting a Shine the Light community gathering is easy ... just follow these 5 steps:

1. **Select** ... a program/activity/event
2. **Prepare** ... for your gathering
3. **Promote**... your gathering
4. **Hold** ... your gathering on June 19
5. **Celebrate** ... your success

1. Select ... a program/activity/event

Here are a few suggestions for what you might do to “Shine the Light on Sickle Cell Disease” and celebrate World Sickle Cell Awareness Day on June 19, 2020.

These programs, activities and events are designed to help you get your community involved in improving access to care and generating support for finding a universal cure for sickle cell disease.

Daytime Ideas:

- Family Fun Day at a local beach or park
- Plant a Tree/Trees in your community
- Start a Community Garden
- Memorial Bubbles to the Sky
- Hold a “Teach-In” about the disease
- Conduct a “Tell Your Story” letter writing/email campaign to your local, state and federal elected officials
- Organize a Blood Drive
- Hold a [non-partisan] Voter Registration Drive
- Ask Your Civic Leaders to Issue a Proclamation marking June 19 as Sickle Cell Awareness Day in your community [see sample proclamation]
- Others?

For maximum impact and greater opportunities to “Shine the Light” consider these additional ideas for an evening gathering.

Nighttime Ideas:

- Organize Homes on Your Block to use red light bulbs on June 19th
- Ask Civic/Business Leaders to Illuminate Their Building with red lights
- Hold Candlelight Vigil – with red candles or red flashlights
- Conduct Porch/Backyard/Street Corner gatherings and talks
- Host a Movie Night outside on the lawn
- Organize a Concert or Open Mic in the park
- Hold an Awareness Walk around the neighborhood
- Others?

In whichever type of event you select, find a way to have the participants ...

- **Wear Red Shirts**
- **Shine Red Lights** [using candles, dollar store lights, flash lights, cell phone lights, light bulbs, glow sticks, glow bracelets, glow necklaces, etc.]

And, make sure to be creative, inclusive and have fun!

2. Prepare ... for your gathering

- Pick a location that is easy for people to get to
- Pick a time that is comfortable for many in your community
- Invite engaging speakers
- Provide [have a local store donate] some refreshments and snacks
- Consider having some music
- Have people introduce themselves to each other at the beginning
- Have elements of this event that speak to the “head - facts” and the “heart - feelings”
- Make sure you have a sign-in sheet to gather names, email addresses and other contact info of those who attend
- Think about what a successful gathering will look like and what data/information you should collect to demonstrate your success
- Other

3. Promote

... Your Gathering

- Create an “event” on your Facebook Page and invite all your FB friends/followers ... social media is a great way to help spread the word
- On your Facebook Page, add “Shine the Light” as a “**Co-Host**” of your gathering ... www.facebook.com/ShineTheLightOnSickleCell ... in this way your event will show up on Shine the Light’s Facebook Page for all of our followers to see. Note: adding Shine the Light as a co-host does not indicate that SiNERGe or STL are organizers of your gathering as individual events are organized and managed solely at the discretion of the primary host organization or individual.

- Like our “Shine The Light” Facebook page and post your gathering on it www.facebook.com/ShineTheLightOnSickleCell
- Tell all of your friends, family members, neighbors, colleagues and others about your gathering ... word or mouth is powerful ... and encourage them to invite those in their networks by posting your event on their website, blog, Facebook pages and groups
- Post event details on your website, blog, Facebook pages and groups that you belong to, too
- Tweet about your gathering – be sure to use hashtag #ShineTheLightOnSickleCell
- Post your gathering on Meetup.com and other event sites
- Put up flyers around your community
- Write a Letter-to-the-Editor of your local paper about the event
- Send a Press Release to your local media outlets [see sample at the end of this guide]
- Contact your local TV/radio stations
- Involve your community hospital and health clinics in your gathering
- Contact and invite your local elected officials and involve them in the gathering

... World Sickle Cell Awareness Day

- **Light the Town Red:** ask your civic leaders to light up the town’s municipal buildings with red lights on June 19.
- **Light Main Street Red:** ask your business leaders to light up their buildings in town with red lights on June 19.
- **Light the Neighborhood Red:** ask your neighbors to use red lights in their windows/porches/vestibules on June 19.
- **Proclamations:** ask your local elected officials to introduce a proclamation declaring June 19th as World Sickle Cell Awareness Day in your community or town [see sample at the end of this guide]

Community Outreach & Engagement – Tips

- Develop an engaging social media campaign that encourages supporters to share posts about going to your gathering and World Sickle Cell Day
- Post on community bulletin boards and like-minded FB pages/groups
- Create an email campaign targeted to organizational volunteers, past donors, or current members to get the word out about your gathering
- Utilize organizational websites and/or newsletters to promote your gathering

Organizational Outreach & Engagement – Tips – Contact and Involve

- Sorority/Fraternity Organizational Chapters
- Churches, Mosques, Temples and other Faith-based institutions
- Neighborhood Community Associations
- Black Women’s Health Imperative
- Civic, Business, Professional and Social organizations
- Youth Associations, including Girls Scouts/Boy Scouts, Big Brothers/Big Sisters, Police Athletic League, Boys and Girls Club of America, YMCA/YWCA, etc.
- Blood Banks
- Sickle Cell Hospital Programs, Sickle Cell Support Groups, Sickle Cell Alliances/Organizations
- National Black Nurses Association
- U.S. Office of Minority Health, National Association of Minority Health
- National Association of Black Social Workers
- Key Stakeholders and Strategic Partners
- Schools, Community Colleges, Universities and Student Associations
- Local, State and Federal Legislators/Elected Officials
- Others

4. Hold ... Your Gathering on June 19

- Make sure that people get a chance to meet each other
- Collect contact info – name, phone, email – from the people who attend
- Take pictures of your gathering ... send them to your elected officials, funders, and other stakeholders ... post them on your social media sites ... and post them to www.facebook.com/ShineTheLightOnSickleCell
- Be sure to use the #ShineTheLightOnSickleCell hashtag
- Thank those who attended and participated

5. Celebrate ... Your Success

- Bravo on holding a successful event
- Send us an email ShineTheLightOnSickleCell@gmail.com to let us know how it went ... how many people participated, what was your event, what made it a success, lessons learned, etc.

RESOURCES

- Background
- Press Release – Sample
- Dear Civic Leader Letter -- Sample
- Proclamation -- Sample

Background

The Shine the Light initiative was launched by leaders of community-based organizations [CBOs] working to increase awareness of sickle cell disease as well as advocacy for services and a universal cure.

The CBO leaders were convened by SiNERGe [Sickle cell Improvement across the NorthEast ReGion through Education] – a multi-state collaborative dedicated to improving care for individuals with sickle cell disease, funded by the U.S. Health Resources and Services Administration, in conjunction with the Sickle Cell Disease Association of America’s 2018 Annual Conference held in Baltimore, Maryland.

The Shine the Light idea was initially suggested by Gloria Rochester [founder and president of Queens Sickle Cell Advocacy Network in NYC] to the CBO leaders as a way to help celebrate and leverage the 10th Anniversary of World Sickle Cell Awareness Day. Embracing the proposed idea, the CBO leaders formed a work group to help organize people in communities all across the nation and around the world to Shine the Light on Sickle Cell Disease on June 19, 2019.

The initial work group was chaired by Zemoria Brandon - Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter; and included Judy Anderson – Sickle Cell Association, Norfolk, Virginia; Linda Armstead – Armstead-Barnhill Foundation for Sickle Cell Anemia; Yvette Armstead – Armstead-Barnhill Foundation for Sickle Cell Anemia; Esme Hillman – Sickle Cell Thalassemia Patients Network; Gloria Rochester – Queens Sickle Cell Advocacy Network; and Nikia Vaughan – Adult and Pediatric to Adult Sickle Cell Clinic, Johns Hopkins University.

The number, range and impact of the Shine the Light events in 2019 was so significant that the CBO leaders again decided to help encourage more of these community gatherings in 2020. This year’s work group is being chaired by Zemoria Brandon and Nikia Vaughan.

We welcome you, too, to help Shine the Light ... by standing up and speaking out to increase awareness, build support networks, raise resources and strengthen our collective resolve to advocate for access to sickle cell services and a cure for sickle cell disease on June 19, 2020.

Press Release – Sample

FOR IMMEDIATE RELEASE

Contact: Your Point of Contact’s Name
Your Point of Contact’s Email
Your Point of Contact’s Phone

Shine the Light on Sickle Cell Disease Community Gathering on June 19 – World Sickle Cell Awareness Day

In celebration of World Sickle Cell Awareness Day – we will be hosting a **“Shine the Light on Sickle Cell Disease”** community gathering on June 19th at [insert who, what, when and where details] _____.

“In our community, together with others in communities across the nation and around the world, we are standing up and speaking out to increase awareness, build support networks, raise critical resources, and strengthen our collective resolve to advocate for access to sickle cell services and a universal cure for sickle cell disease” states _____ who is one of the local Shine the Light on Sickle Cell Disease organizers.

In 2008, The General Assembly of the United Nations passed a regulation designating June 19 as World Sickle Cell Awareness Day to be held annually starting in 2009. Since then, it has served as a way to increase awareness of this worldwide public health concern and the struggles that those with Sickle Cell Disease (SCD) and their families go through on a daily base.

This year, Sickle Cell Disease community-based organizations are organizing gatherings all across the nation and around the world to “Shine the Light on Sickle Cell Disease” while celebrating World Sickle Cell Disease Awareness Day in order to elevate awareness of this serious public health concern affecting more than 100 million people around the world.

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Dear Civic Leader Letter - Sample

Dear Honorable _____:

Our community based organization, _____, is hosting a community gathering on June 19 to “Shine the Light on Sickle Cell Disease” and celebrate World Sickle Cell Awareness Day – as established by the United Nations.

Our desired goal is to increase awareness, build support networks, raise critical resources, and strengthen our collective resolve to advocate for access to sickle cell services and a cure for sickle cell disease. Toward this end, we are requesting that you:

- Introduce and pass a resolution acknowledging June 19th as Sickle Cell Awareness Day in our community, and
- Seek to have our civic buildings illuminated in red on June 19th to increase awareness of this disease that significantly impacts members of our community.

Sickle cell disease (SCD) is one of the world’s largest leading genetic diseases that has severe physical, psychological and social consequences for those affected and their families. In its most homozygote form, it is one of the most lethal genetic diseases affecting 90,000 to 100,000 Americans. As such, SCD is a major public health concern. Studies show that the annual cost of medical care in the US for people who suffer from SCD exceeds \$1.1 billion.

On behalf of the Sickle Cell Community, we would greatly appreciate your help in shining a light on this disease and thereby helping to enhance the quality of life for families and individuals affected with SCD. Thank you in advance for your support of the sickle cell community.

Sincerely,

Proclamation – Sample
“Shine the Light on Sickle Cell”
World Sickle Cell Awareness Day – June 19, 2020

WHEREAS, the General Assembly of the United Nations on December 22, 2008 adopted a resolution, drafted by the Democratic Republic of Congo, to recognize sickle cell disease as a serious world health problem on June 19 of each year – starting in 2009 – at the national and international levels; and

WHEREAS, the UN has declared June 19 World Sickle Cell Awareness Day; and

WHEREAS, it is recognized that sickle-cell disease is one of the world’s foremost genetic diseases, that it has severe physical, psychological and social consequences for those affected and their families, and that in its homozygote form it is one of the most lethal genetic diseases; and

WHEREAS, there is a serious need to raise public awareness about sickle-cell disease and to eliminate harmful prejudices associated with the disease; and

WHEREAS, members of our community are organizing a “Shine the Light on Sickle Cell Disease” event to celebrate World Sickle Cell Awareness Day, and

WHEREAS, our community is hosting a gathering to “Shine the Light on Sickle Cell Disease” and in so doing to help increase awareness, build support networks, raise critical resources, and strengthen our community’s collective resolve to advocate for access to sickle cell services and a universal cure for sickle cell disease;

NOW, THEREFORE BE IT RESOLVED, that June 19, 2020 is proclaimed to be:

“Shine the Light on Sickle Cell Disease - World Sickle Cell Day Awareness Day”

Thank You!

Dear Shine the Light on Sickle Cell Host/Organizer –

We wish you tons of success as you gather members of your community to Shine the Light on Sickle Cell Disease and celebrate World Sickle Cell Awareness Day.

Please keep us posted as you prepare for and hold on your community gathering.

Your effort to help increase awareness and support for finding a universal cure is greatly appreciated!

- Shine the Light - Work Group - 2020

SiNERGe Community Based Organizations' Collective Impact Initiative

- Co-Chair - Zemoria Brandon, BSW, Administrator/Social Worker, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
- Co-Chair - Nikia Vaughan -- Communications Coordinator/Community Health Worker, Adult and Pediatric to Adult Sickle Cell Clinic, Johns Hopkins University
- Abena Acheampong – Research Program Assistant, Johns Hopkins Medicine
- Judy Anderson – Executive Director, Sickle Cell Association, Norfolk, Virginia
- Linda Armstead – Board Member, Armstead-Barnhill Foundation for Sickle Cell Anemia
- Yvette Armstead – CEO, Armstead-Barnhill Foundation for Sickle Cell Anemia
- Esme Hillman – CHW/Outreach Worker/Dinner Dance Chair, Sickle Cell & Thalassemia Patients Network (SCTPN)
- Murine Lusakweno-Chandler – Outreach Liaison/Educator, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
- Shanta Robertson – Executive Director, Maryland Sickle Cell Disease Association
- Gloria Rochester – President, Queens Sickle Cell Advocacy Network
- Sarai Santiago – Community Health Worker, Sickle Cell Thalassemia Patients Network (SCTPN)
- Wally Smith – Florence Neal Cooper Smith Professor of Sickle Cell Disease, Virginia Commonwealth University (VCU)