



# Shine the Light On Sickle Cell: A Movement

Presentation to the SCDA Leadership Academy

May 20, 2021

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Beverley Francis-Gibson, SCDA President/CEO and Dr. Karen Proudford, SiNERGe CBO Lead

## Welcome you to ... Shine the Light

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**A day of  
community action**

**WORLD  
SICKLE CELL DAY  
JUNE 19, 2021**



# The Partnership Behind Shine The Light

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SiNERGē and Sickle Cell Disease Association of America, Inc. [SCDAA] are collaborating with sickle cell advocacy groups, community-based organizations, hospitals, governments and other key stakeholders in the sickle cell community to Shine The Light On Sickle Cell – a campaign to celebrate World Sickle Cell Awareness Day as designated by the United Nations.

On June 19<sup>th</sup> - and throughout the month - individuals and organizations are hosting a number of awareness and advocacy activities across the country [and around the globe].

# Shine the Light – Video

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Created by:

Murine A. Lusakweno Chandler

Shine the Light Steering Committee

Social Media Sub-Committee Team Leader

SCDAA/PDVC CHW | Outreach Liaison





Today we will explore:  
**How to Shine The Light on Sickle Cell Disease**  
in your community on June 19<sup>th</sup>

**Leading Today's Discussion:**

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ZEMORIA BRANDON -  
CO-CHAIR, SHINE THE  
LIGHT STEERING  
COMMITTEE; SCDA  
PHILADELPHIA/DELAWARE  
VALLEY CHAPTER



DONNETTE CARROLL -  
CO-CHAIR, SHINE THE  
LIGHT STEERING  
COMMITTEE; SICKLE  
CELL THALASSEMIA  
PATIENTS NETWORK,  
(SCPTN), BOARD  
PRESIDENT

# How to Shine the Light: A Movement

## Thursday, May 20: 2:30 pm – 3:30 pm

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### AGENDA

- Greetings- Beverley Francis-Gibson, Dr. Karen Proudford
- Shine the Light – Video – Murine A. Lusakweno Chandler
- Welcome and Overview- Zemia Brandon and Donnette Carroll
- Sample Shine the Light Efforts:– Zemia Brandon and Donnette Carroll
  - Proclamation
  - Hospital Collaboration
  - Landmark Illumination
- Practice Session: Role Plays – Facilitated by Zemia Brandon
- Post-Poll
- Q&A
- Resources
- Appreciations & Closure

# Purpose of Shine The Light

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- Increase Awareness
- Build Support Networks
- Highlight the Need for Critical Resources
- Strengthen Our Collective Resolve

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



# History of Shine the Light

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- Launched by leaders of Sickle Cell community-based organizations [CBOs]
- Initiated during a meeting convened by SiNERGe [Sickle cell Improvement across the NorthEast ReGion through Education] at the SCDAAs 2018 Annual Conference
- SiNERGe is a multi-state collaborative dedicated to improving care for individuals with sickle cell disease, funded by the U.S. Health Resources and Services Administration
- Initially suggested by Gloria Rochester [Queens Sickle Cell Advocacy Network in NYC] to help celebrate the 10<sup>th</sup> Anniversary of World Sickle Cell Awareness Day in 2019
- CBO leaders formed a work group to 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 impact of the Shine the Light events in 2019 was so significant that the CBO leaders decided to encourage more community gatherings in 2020 and again in 2021



# Last Year's Highlights

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## 2020 HIGHLIGHTS

Here's a look at highlights from the 2020 Shine the Light Campaign



# Hosting a Shine The Light Community Gathering

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Here are the are 5 steps:



# Select

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## DAYTIME IDEAS

In Person	Virtually
Family Fun Day at a local beach or park	Family Fun Day At Home
Plant a tree or trees in your community ... Start a community garden	Plant a garden on your balcony or in your backyard
Ask for city/town officials to light municipal buildings and bridges red	Ask for city/town officials to light municipal buildings and bridges red
Memorial Bubbles to the Sky	Memorial Bubbles to the Sky
Hold a “teach-in” about the disease	Hold a “teach-in” about the disease
Conduct a “tell your story” letter writing/email campaign to your local, state and federal elected officials	Conduct a “tell your story” letter writing/email campaign to your local, state and federal elected officials
Organize a blood drive	
Ask your civic leaders to issue a proclamation marking June 19 as Sickle Cell Awareness Day in your community [ask us for a sampleproclamation]	Ask your civic leaders to issue a proclamation marking June 19 as Sickle Cell Awareness Day in your community [ask us for a sampleproclamation]
Hold a non-partisan voter registration drive	Encourage people to register and vote

# Select

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

In Person	Virtually
Organizing entire blocks and building to use red light bulbs on June 19 <sup>th</sup>	Organizing entire blocks and building to use red light bulbs on June 19 <sup>th</sup>
Ask civic/business leaders to illuminate their building with red light	Ask civic/business leaders to illuminate their building with red lights
Hold candlelight vigil – with red candles or red flashlights	Hold candlelight vigil – with red candles or red flashlights
Conduct porch/backyard/street corner gatherings and talks	Hold Zoom virtual gatherings and talks
Host a movie night outside on the lawn	Host a movie night at home and via Zoom or phone talk about it with friends as you watch
Organize a concert or open mic in the park	Organize a concert or open mic via Zoom
Hold an awareness walk around the neighborhood BUT wear a mask and keep 6 feet apart	Hold an awareness walk around the neighborhood BUT wear a mask and keep 6 feet apart

# **Sample Shine The Light Efforts**

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Proclamation  
Hospital Collaboration  
Landmark Illumination

# Proclamation Linda Armstead Armstead-Barnhill Foundation for Sickle Cell Anemia Bambrills, Maryland



Dear Honorable Governor Larry Hogan:

Our community-based organization, the Armstead-Barnhill Foundation for Sickle Cell Anemia, is recognizing on June 19, 2020, World Sickle Cell Awareness Day. World Sickle Cell Awareness Day was established by the United Nations in December 2008. We would like your assistance in helping us "Shine the Light on Sickle Cell Disease".

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 the State Capital 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,

Linda Armstead, Board Member

Armstead-Barnhill Foundation for Sickle Cell Anemia

The Armstead-Barnhill Foundation for Sickle Cell Anemia

P.O. Box 836

Gambrills, MD 21054

[www.CureSickleCell.com](http://www.CureSickleCell.com)

[findcure@aol.com](mailto:findcure@aol.com)

[facebook.com/ArmsteadBarnhill](https://facebook.com/ArmsteadBarnhill)

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## The State of Maryland Proclamation

*From the Governor of the State of Maryland*

**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,** June 19, 2020 will be recognized as World Sickle Cell Awareness Day; and

**WHEREAS,** It is acknowledged 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

**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,** To mark World Sickle Cell Awareness Day communities throughout the world gather to "Shine the Light on Sickle Cell Disease" to increase awareness, build support networks, raise critical resources, and strengthen the community's collective resolve to advocate for access to sickle cell services and a cure for sickle cell disease.

**NOW, THEREFORE, I, LAWRENCE J. HOGAN, JR., GOVERNOR OF THE STATE OF MARYLAND, do hereby proclaim JUNE 19, 2020 as WORLD SICKLE CELL AWARENESS DAY in Maryland and call upon the people of our state to join in this observance.**



Given Under My Hand and the Great Seal of the State of Maryland,  
this 19th day of June, 2020

*Lawrence J. Hogan, Jr.*  
Governor

*Robert K. L. Loefer*  
Lt. Governor

*John C. Womack*  
Secretary of State

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# Hospital Collaboration

Andrea M. Matthews  
Children's Sickle Cell Foundation, Inc.  
Pittsburgh, PA

World  
Sickle Cell  
Day

FRIDAY JUNE 19TH 2020



Shine the Light on SCD:  
New Therapies and Technology - Zoom Event

JUNE 19, 2020 | 1-3PM

1:00PM - Welcome - Michael L. Matthews, Executive Director  
1:05PM - World Sickle Cell Day Overview  
1:15PM - Coping Strategies - Shayon Dobson-Lynn, LCSW  
1:30PM - Therapies Presentation with Q&A  
1:45PM - New Technologies Presenting - LWSC@Mobile App  
2:00PM - Presenting Sponsor Presentation with Q&A  
2:10PM - Sickle Cell Community Perspectives  
2:30PM - New Technologies - SickleOptions.org  
2:45PM - Therapies Presentation with Q&A  
2:55PM - Closing Remarks/Conclusion

**pre-register**

[CLICK HERE TO REGISTER](#)

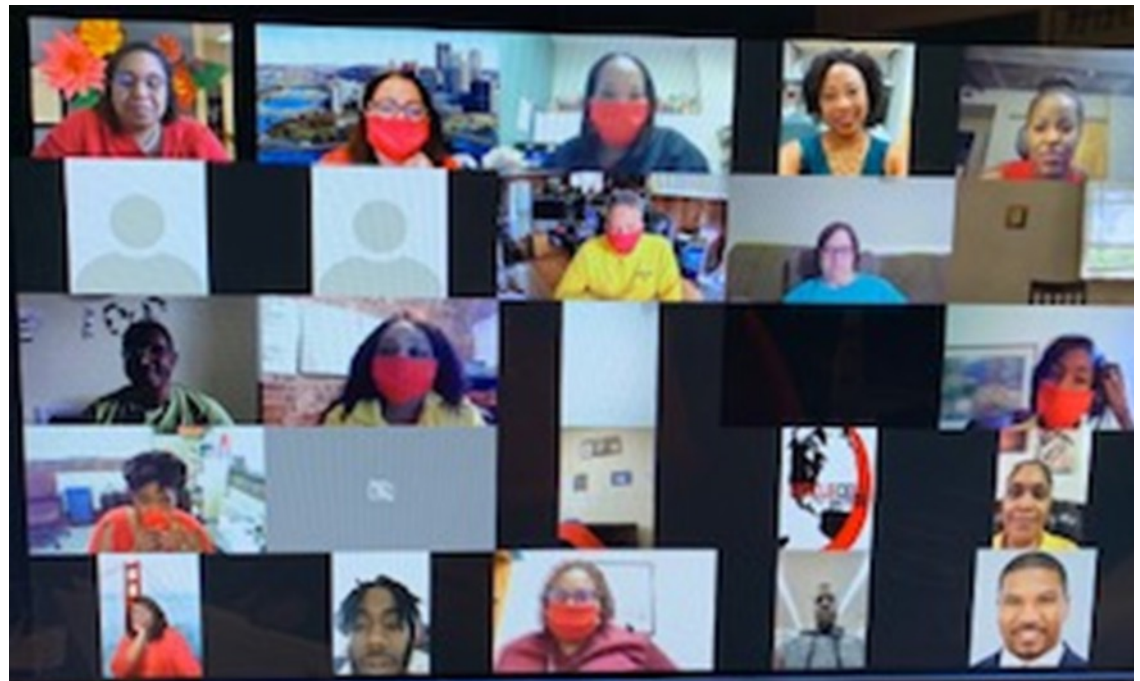
The first 100 to register before  
June 12th receive a red mask for  
#MasksupforSCD

Sponsorships are available!  
Click or call 412-287-4585 or email  
mmatthews@cscfkids.org



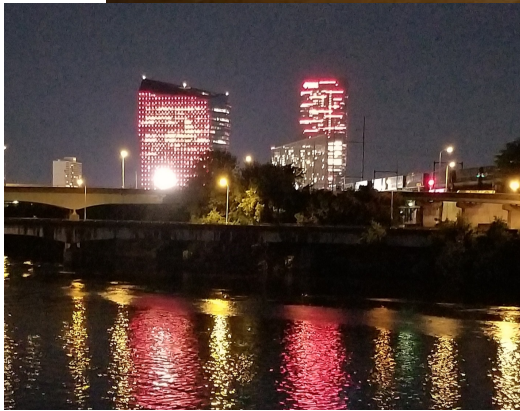
Children's  
Sickle Cell  
Foundation, Inc.

Grove Business Center - 226 Paul Street - Pittsburgh, PA 15211 - 412-488-2723





Landmark Illumination  
Zemoria Brandon  
SCDAA Philadelphia-Delaware Valley Chapter  
Philadelphia, Pennsylvania





# Stages of the Ask

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The Opening: *Establish relationship*

The Case/Share Your Story: *What is the problem?*

The Ask: *How can they help? Be specific.*

The Closing: *Thank and summarize*

# Practice Session: Making the Ask

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- Mayor/Official ... to light City Hall or landmark
- Elected official ... to issue proclamation
- Hospital Administrator ... to seek the hospital's involvement in your STL event



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# Q&A

# Call to Action

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## ➤ **STAND UP**

Shine the Light on Sickle Cell is a national initiative to bring attention to SCD and to celebrate World Sickle Cell Awareness Day, which is June 19th

## ➤ **SPEAK OUT**

Help organize and/or attend a Shine the Light on Sickle Cell in your community on June 19th

## ➤ **SPREAD THE WORD**

Go to the “Shine the Light Event” page on Facebook page and click “Going” ... then invite all your family, friends and colleagues to the STL event too!

## ➤ **SHARE YOUR EVENT**

Tell others about your Shine the Light On Sickle Cell gathering by creating your own event on your Facebook page and by posting about it on the Shine the Light Facebook Event page

## ➤ **MORE INFO**

To learn more and to find out how to organize a Shine The Light event in your community, check out the Shine The Light Community Gathering Guide ... email us for a free copy at

**[ShineTheLightOnSickleCell@gmail.com](mailto:ShineTheLightOnSickleCell@gmail.com)**

## Resources & More

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- Shine the Light – A Guide to Community Gatherings  
<https://wepsicklecell.org/sinerge/shine-the-light/#1617184229232-ed964795-4f47>
- Shine the Light Email: [ShineTheLightOnSickleCell@gmail.com](mailto:ShineTheLightOnSickleCell@gmail.com)
- Shine the Light Facebook Event  
[https://www.facebook.com/events/185715520056180/?active\\_tab=about](https://www.facebook.com/events/185715520056180/?active_tab=about)
- Shine the Light Video- <https://youtu.be/f2TqqCWBZQU>

# Shine the Light - Work Group - 2021

SiNERGe Community Based Organizations' Collective Impact Initiative

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**Zemoria Brandon** - Co-Chair, BSW, Administrator/Social Worker, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter

**Donnette Carroll** - Co-Chair, SHINE THE LIGHT STEERING COMMITTEE, SICKLE CELL THALASSEMIA PATIENTS NETWORK, (SCPTN), BOARD PRESIDENT

**Judy Anderson** - Executive Director, Sickle Cell Association, Norfolk, Virginia

**Yvette Armstead** - CEO, Armstead-Barnhill Foundation for Sickle Cell Anemia

**Jacqueline Baker** - Founder, The Westchester Sickle Cell Advocacy Network

**Sakiyah Burwell-Darden** - Executive Assistant/CHW, Sickle Cell Association of New Jersey

**Beverley Francis-Gibson** - President & CEO, Sickle Cell Disease Association of America

**Barbara Harrison** - Director at Large, Sickle Cell Association of the National Capital Area, Inc

**Linda Howard** - Member Services Coordinator, Sickle Cell Disease

Association of America

**Betty Johnson** - SiNERGe Liaison, Association for the Prevention of Sickle Cell Anemia Harford/Cecil Counties Inc.

**Mary Lamar** - Executive Director, Sickle Cell Association of New Jersey

**Meryl Lancaster** - Board Member, Citizens for Quality Sickle Cell Care

**Sabrina Lewis** - Ambassador of Wellness, CHW, Sickle Cell Thalassemia Patients Network (SCTPN)

**Murine Lusakweno Chandler** – Outreach Liaison/Educator, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter

**Crystal Rivas** - Administrative Assistant, Candice's Sickle Cell Fund

**Shanta Robertson** - Executive Director, Maryland Sickle Cell Disease Association

**Sarai Santiago** - Community Health Worker, Sickle Cell Thalassemia Patients Network (SCTPN)

**Stanley Simpkins** - Executive Director, Sickle Cell Disease Association, Philadelphia/Delaware Valley Chapter

**Thank You ... for helping to**  
**Shine the Light on Sickle Cell Disease**

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**June 19, 2021**



Shine the Light is supported by the Health Resources and Services Administration (HRSA) as part of the Sickle Cell Disease Treatment Demonstration Project. For more information, visit [HRSA.gov](https://www.hrsa.gov).



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**“Every mighty river ...  
begins with a single rain  
drop.”**

**- African Proverb**