



SiNERGē
NORTHEAST REGIONAL
SICKLE CELL COLLABORATIVE



Host: Andrea Matthews
Children's Sickle Cell Foundation, Inc.
Pittsburgh, Pennsylvania



SiNERGē CBO ECHO - a Peer-to-Peer Learning Session on

How to Shine the Light: A Movement



SiNERGe CBO ECHO - a Peer-to-Peer Learning Session on

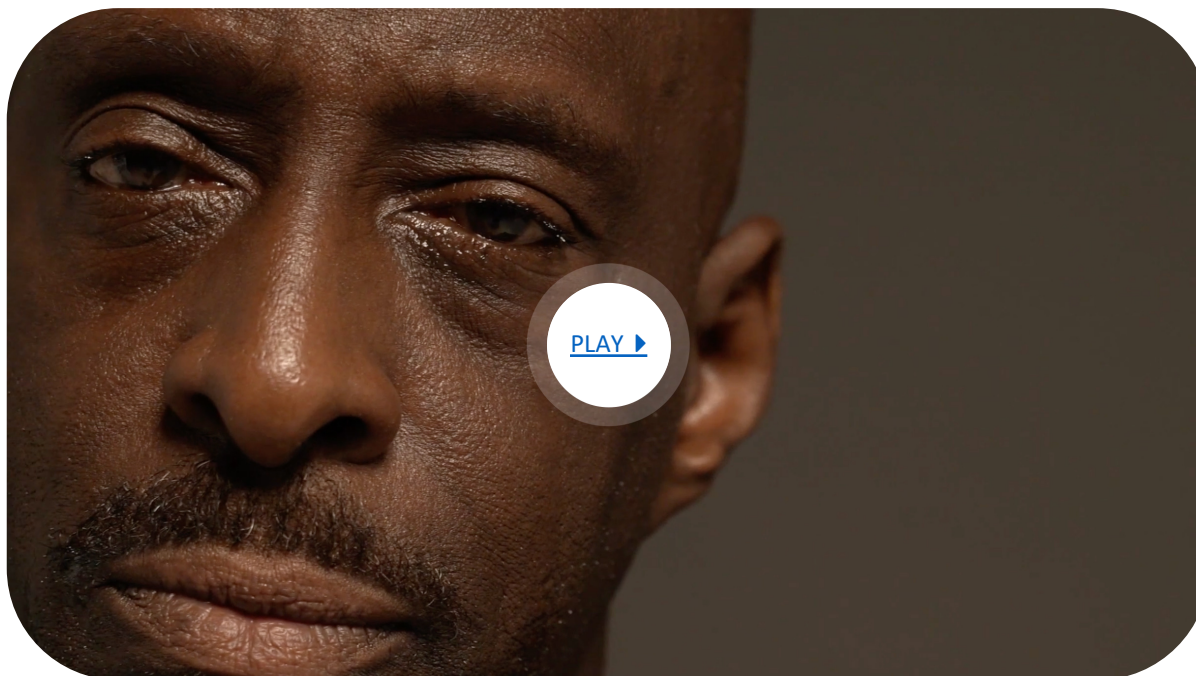
How to Shine the Light: A Movement



Shine the Light Video 2022

Created by: Murine A. Lusakweno-Chandler

Shine the Light Steering Committee, Social Media Sub-Committee Chair, SCDAAPDVC - Director of Programs, CHW





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Pre-Poll





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How to Shine the Light: A Movement



Wednesday, April 20, 3:00 pm – 4:00 pm EST

AGENDA

- Pre-Poll
- Shine the Light – Video – Murine A. Lusakweno Chandler
- Welcome & Overview – Zemia Brandon
- Case Studies: Challenges & Successes –
 - Proclamation - Judy Anderson
 - Hospital Collaboration – Andrea Matthews
 - Landmark Illumination – Zemia Brandon
- How to Make “The Ask” – Steven Rivelis
- Practice Session: Role Plays – Facilitated by Zemia Brandon
- Post-Poll
- Q&A
- Resources
- Appreciations & Closure



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How to Shine the Light: A Movement



Leading Today's Discussion



**Zemoria
Brandon**

—
Chair, Shine the Light
Steering Committee; SCDA
Philadelphia - Delaware
Valley Chapter



**Murine A.
Lusakweno-
Chandler**

—
Shine the Light Steering
Committee, Social Media
Sub-Committee Team
Leader; SCDA/PDVC,
CHW Outreach Liaison



**Judy
Anderson**

—
Shine The Light Steering
Committee. Public Relations
Sub-Committee
Chairperson; Executive
Director, Sickle Cell
Association – Hampton
Roads, VA



**Andrea M.
Matthews**

—
Founder, Children's Sickle
Cell Foundation,
Inc./SiNERGe Project ECHO
CBO Co-Lead



**Steven
Rivelis**

—
SiNERGe Consultant, CEO
Rivelis & Associates



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Shine The Light – A Collaboration



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

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



How to Shine the Light: A Movement

Purpose of Shine The Light

- 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





How to Shine the Light: A Movement

History of Shine the Light

- Launched by leaders of Sickle Cell community-based organizations [CBOs]
- Initiated during a meeting convened by SiNERGe CBO [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 10th 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, 2021 and again in 2022



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2021 Highlights

128

EVENTS

25

STATES + DC + PR

122

ORGANIZATIONS

24.7K

FACEBOOK
USERS REACHED

90

TWEETS

9.3K

TWEET
IMPRESSIONS



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Hosting a Shine The Light Community Gathering





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Case Study Interviews: Challenges & Successes

Proclamation

Judy Anderson

Hospital Collaboration

Andrea Matthews

Landmark Illumination

Zemoria Brandon

Key Tactics & Techniques



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Proclamation



Judy Anderson

Shine The Light Steering Committee.
Public Relations Sub-Committee
Chairperson; Executive Director, Sickle
Cell Association – Hampton Roads, VA

City of Norfolk
Virginia

Proclamation

WHEREAS, on December 22, 2008, the General Assembly of the United Nations adopted a resolution drafted by the Democratic Republic of Congo to recognize sickle cell disease as a serious world health problem; and

WHEREAS, the United Nations has declared June 19th of each year as World Sickle Cell Awareness Day; and

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

WHEREAS, the State of Virginia has approximately 5,000 persons living with Sickle Cell Disease of which about 2,500 persons are living in the Hampton Roads region; and

WHEREAS, the Sickle Cell Association, Inc. is organizing a "Shine the Light on Sickle Cell Disease" event to help increase awareness, build support works, 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, I, KENNETH COOPER ALEXANDER, Mayor of the City of Norfolk, do hereby proclaim, Saturday, June 19, 2021 as

WORLD SICKLE CELL AWARENESS DAY

in the City of Norfolk and urge all citizens to help raise public awareness of individuals and families affected by this disease to ensure they have access to quality, affordable care, and that research of this disease continues.

Given under my hand this 19th day of June 2021.




KENNETH COOPER ALEXANDER Ph.D.
MAYOR



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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

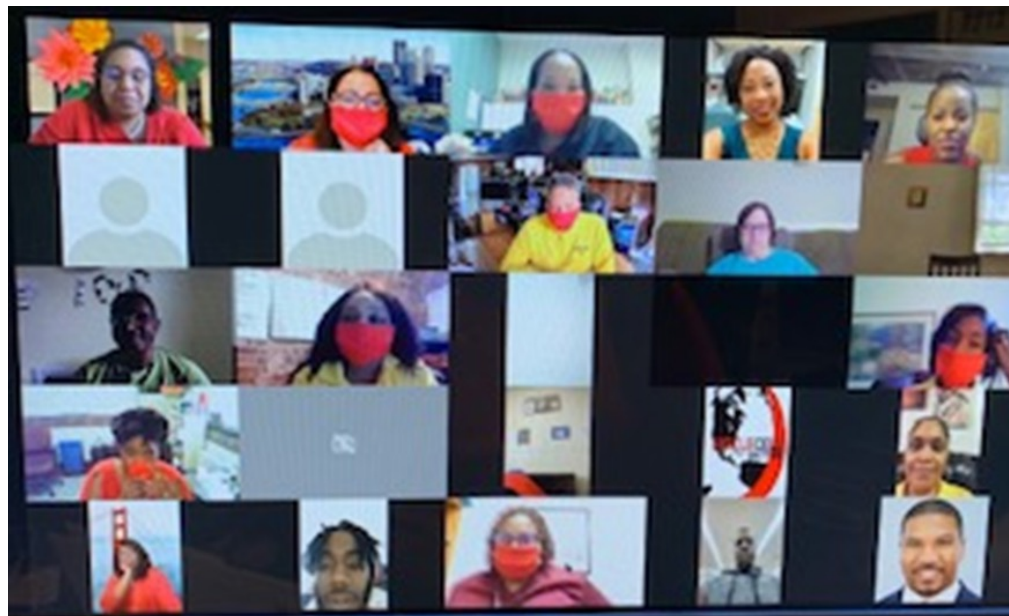
The first 100 to register before
June 12th receive a red mask for
#MasksupforSCD

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 15201 - 412-488-2723





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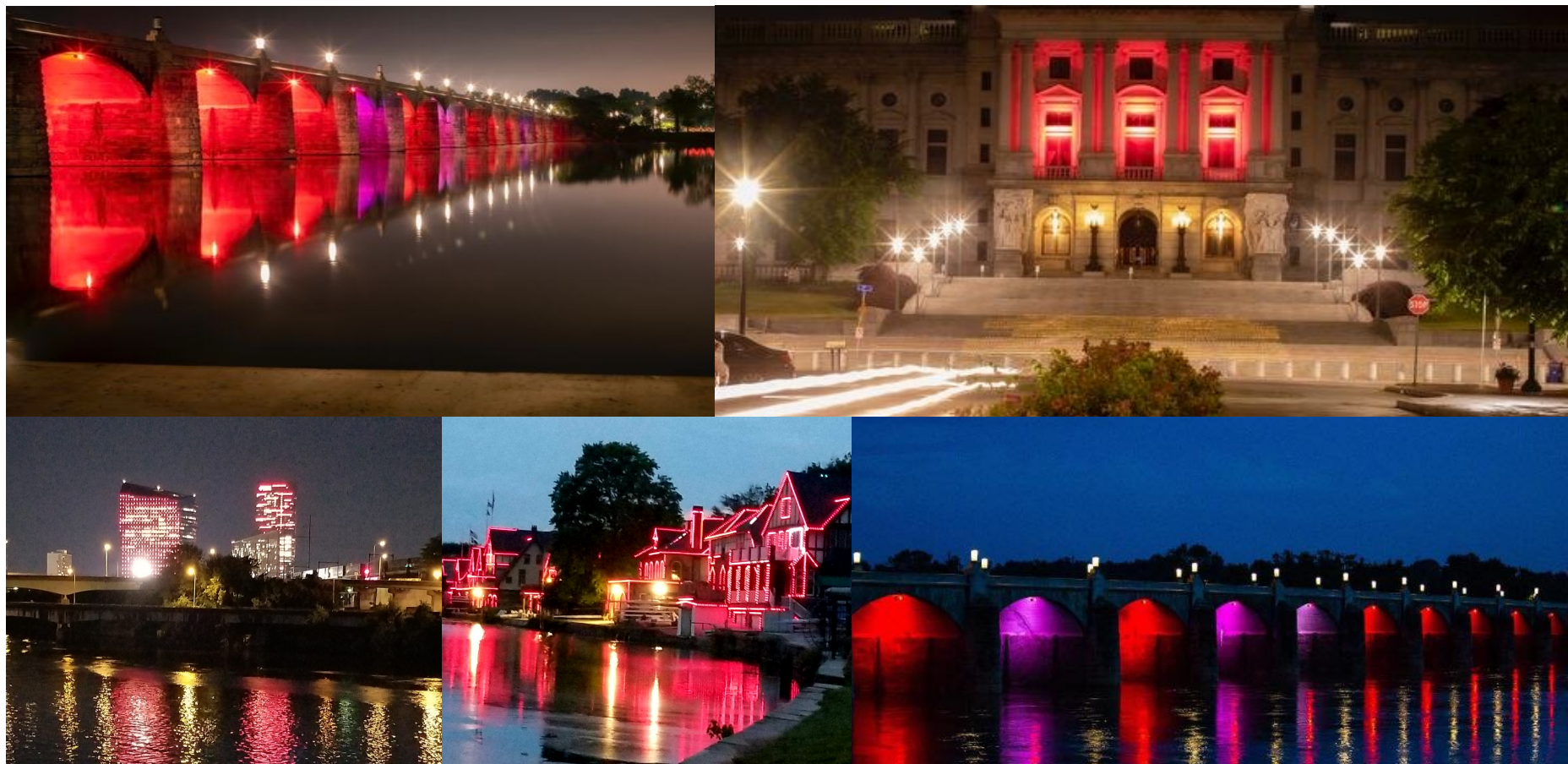
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Landmark Illumination in Red

Zemoria Brandon

SCDAA Philadelphia-Delaware Valley Chapter - Philadelphia, PA





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How to make ... “The Ask”

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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How to make ... The Ask: **The Five Knows**

- 1. Actors**
- 2. Issue**
- 3. Yourself**
- 4. Message**
- 5. The Stages of the Ask**

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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#5 Know the ... Stages of the Ask

I. OPENING

II. SIP – Your Case Presentation

III. CLOSING

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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#5 Know the ... Stages of the Ask

I. OPENING

- Introductions
- Common Ground/Linkages & Intersections
- Listen and Hear

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#5 Know the ... Stages of the Ask

II. SIP – Your Case Presentation

Situation: *What is the issue/problem/concern?*

Importance/Impact: *Why is this important/What is the impact?*

- Conversational
- Complete and succinct
- Answer questions
- Listen for points of agreement ... reinforce
- Listen for objections ... answer

Proposal: *What is the request – How can they help?*

- Be specific
- Be confident
- Be silent afterward ... but don't let them say no



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#5 Know the ... Stages of the Ask

III. CLOSING

- Repeat outcome/understanding
- Confirm follow-up
- Express appreciation
- Follow-Up

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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Practice Session: Role Plays

Make “The Ask” ...

Elected Official

... to issue Proclamation

Hospital Administrator

... to seek the Hospital's involvement in your event

Mayor/Official Representative

... to light City Hall/community landmarks in red

Feedback: What worked? What could be improved?



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The Ask Practice Session:

Elected Official ...
to issue proclamation

Opening

SIP: Situation ... Importance ... Proposal

Closing



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The Ask Practice Session:

Hospital Administrator ...
to seek the hospital's involvement in event

Opening

SIP: Situation ... Importance ... Proposal

Closing



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The Ask Practice Session:

Mayor/Official Representative ...
to light City Hall/community landmarks in red

Opening

SIP: Situation ... Importance ... Proposal

Closing



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Q&A



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Post-Poll





How to Shine the Light: A Movement

Call to Action

➤ 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



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Join us for the next learning session:



Mental Health and Developing Resources for CBOs

When: Wednesday, May 18, 2022

Time: 3pm – 4pm

Guest Speaker: Mary Bartlett, President, NY Chapter of the National Alliance of Mental Illness will talk about NAMIs resources and opportunities to collaborate for the benefit of SCD families.

Host: Desiree Scott



SINERGE



“There is no power for change
greater than a community
discovering what it cares about”

Margaret J. Wheatley



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Shine the Light Committee – 2022

Shine The Light Planning Committee

Zemoria Brandon - *Chair, Shine the Light Planning Committee*

Administrator/Social Worker, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter

Public Relations Subcommittee

Judy Anderson - *Chair, STL Public Relations Subcommittee*

Executive Director, Sickle Cell Association, Norfolk, Virginia

Public Relations Subcommittee Members:

Regina Hartfield (SCDAA HQ), Betty Johnson (MD), Mary Bentley LaMar (NJ), Stanley Simpkins (PA)

Outreach Subcommittee

Barbara Harrison - *Chair, STL Outreach Subcommittee*

Director at Large, Sickle Cell Association of the National Capital Area, Inc.

Outreach Subcommittee Members:

Esme Hilman (NY), Mark Goodwin (NY), Sabrina Lewis (NY), Artisha McCoy (NY), Vivian Okowuagwe (NY), Darlene Young (NJ)

Social Media Subcommittee

Murine Lusakweno-Chandler - *Chair, STL Social Media Subcommittee*

Director of Programs, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter

Social Media Subcommittee Members:

Deyaniris Espinal (PA), Lya Jackson (NJ), Kieyeitha Ward (NJ)



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Resources and More

(Click on links below)

[Shine the Light webpage](#)

[How to Make the Ask](#)

[Shine the Light Community Gathering Guide](#)

[Shine the Light Facebook Page](#)

[Email us](#)



Thank You

for helping to

Shine the Light on Sickle Cell Disease
June 19, 2022

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).