



**SiNERGe 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

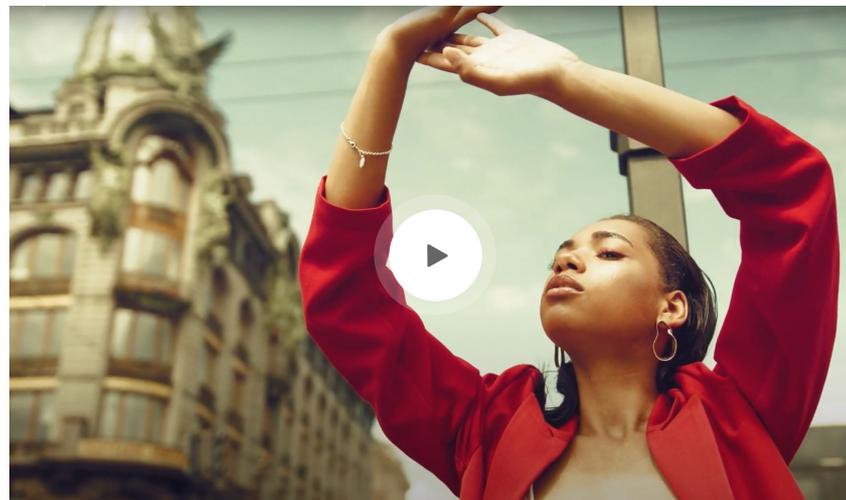


# “Shine the Light on Sickle Cell: Celebrating 5 Years - Looking Back ... Moving Forward”

Shine the Light – 2023 Video created by:

**Murine A. Lusakweno Chandler**

Shine the Light Steering Committee  
Social Media Committee Co-Chair  
SCDAA/PDVC - Director of Programs, CHW





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## Pre-Poll





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Wednesday, April 17: 3:00 pm – 4:30 pm EST

## AGENDA

- Welcome – Mark Goodwin
- Shine the Light – Video – Murine A. Lusakweno Chandler
- Pre-Poll
- Agenda & Overview – Zemoria Brandon
- Case Studies: Challenges & Successes
  - Proclamation – Mary Bentley LaMar
  - Hospital Collaboration – Andrea M. Matthews
  - Landmark Illumination – Zemoria Brandon
- How to Make “The Ask” – Steven Rivelis
- Practice Session: Role Plays – Facilitated by Zemoria Brandon
- Q&A
- Post-Poll
- 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; SCDAA  
Philadelphia - Delaware  
Valley Chapter



**Murine A.  
Lusakweno  
Chandler**

Shine the Light Steering  
Committee, Social Media  
Committee Co-Chairperson;  
SCDAA/PDVC, CHW



**Mary  
Lamar**

Chair, Unaffiliated Patients  
Committee; *founder and  
Executive Director of The  
Sickle Cell Association of  
New Jersey (SCANJ)*



**Andrea M.  
Matthews**

Founder, Children's Sickle  
Cell Foundation,  
Inc./SiNERGe –  
Data Collection Lead



**Steven  
Rivelis**

SiNERGe CBO Consultant  
Rivelis & Associates, CEO –  
*Advocates for Social Good &  
Social Justice*



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## How to Shine the Light: A Movement



# Shine The Light – A Collaboration



SiNERGe, together with the Sickle Cell Disease Association of America, Inc. [SCDAA], sickle cell advocacy groups, community-based organizations, hospitals, governments and other key stakeholders in the sickle cell community, is organizing 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].



## 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 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 over the past number of years has been so significant that the CBO leaders decided to continue to encourage these days of community action on World Sickle Cell Day to further increase awareness and advocacy



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## 2023 Highlights

253

EVENTS / ACTIVITIES / MENTIONS

20

STATES + DC + VI

17

COUNTRIES

111

ORGANIZATIONS

870K

AD IMPRESSIONS

1.2K

META FOLLOWERS



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## Hosting a Shine The Light Community Gathering





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SICKLE CELL COLLABORATIVE



# Case Study Interviews: Challenges & Successes

- Proclamation – Mary LaMar
- Hospital Collaboration – Andrea M. Matthews
- Landmark Illumination – Zemoria Brandon
- ☐ Key Tactics & Techniques



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# Proclamation

Mary LaMar  
Founder and Executive Director  
Sickle Cell Association of New Jersey (SCANJ)





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## How to Shine the Light: A Movement



Develop and Maintain Hospital Partnerships



Plan events that focus on the strengths of care and community



Consider Awareness Networks



Plan a debrief session



Celebrate and Thank



# Hospital Collaboration

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





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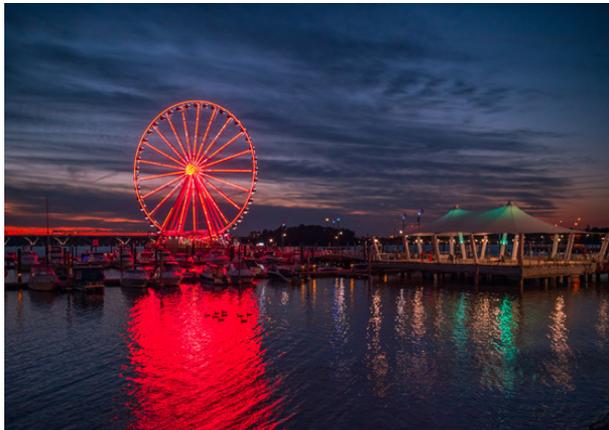
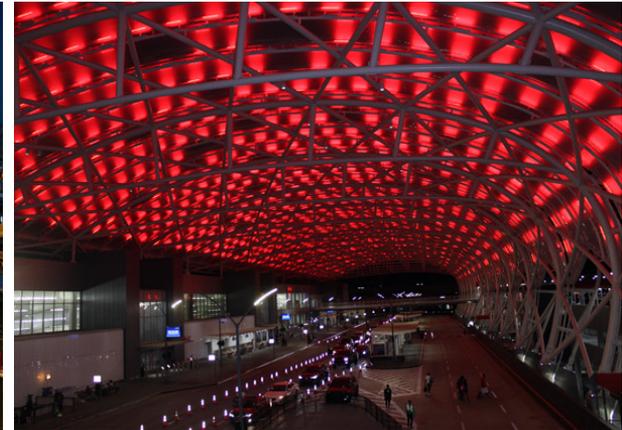
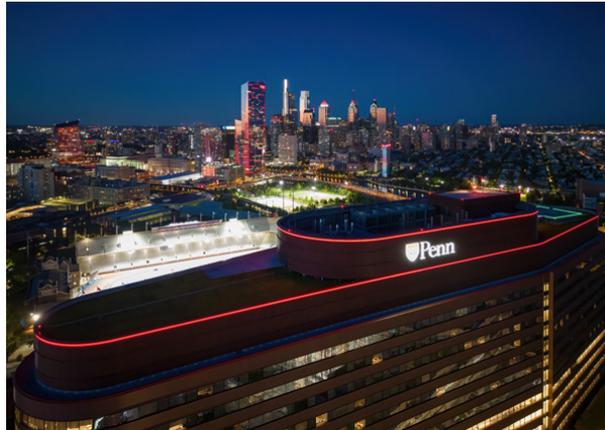
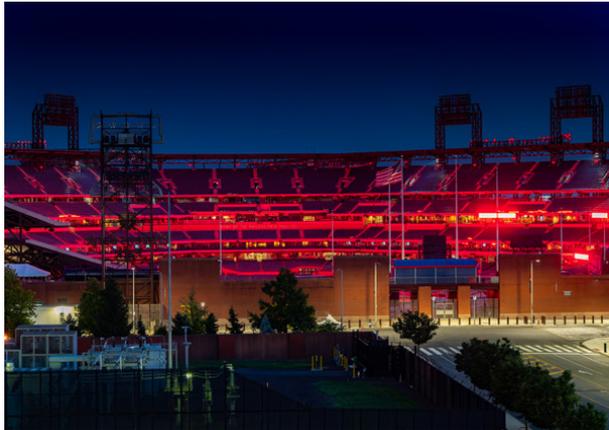
# How to Shine the Light: A Movement



## Landmark Illumination in Red

**Zemoria Brandon**

SCDAA Philadelphia-Delaware Valley Chapter  
Philadelphia, Pennsylvania





## How to Shine the Light: A Movement

# How to Request Illuminating Buildings in Red

- Contact, Executive Director, Building and Management Owners Association (BOMA) in your area.
- Request listing of contact information for building owners and key landmarks (buildings, bridges, fountains, airports, city, state and federal buildings, sports stadiums, etc.) who light up their locations.
- Send letter of request (sample template in Community Gathering Guide) to individual building contacts about lighting up on the following dates: June 19, week/weekend prior to June 19 or week of June 19 or entire month of June.
- Include STL flyer, key messages, call to action and community gathering guide with letter of request.
- Invite building owners to post STL information in their calendar of events, social media and share with their network.
- Send a thank you letter after STL and invite building owners to participate for the following year.



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## How to Shine the Light: A Movement



# How to make ...

# “The Ask”

Developed by: Steven Rivelis, CEO – Rivelis & Associates

*Advocates for Social Good & Social Justice*

RivelisSteven@gmail.com



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

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

\* = Please go to the end of this PPT for additional resources on each of these “Knows”

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## Stages of the Ask

**I. OPENING**

**II. SIP – Your Case Presentation**

**III. CLOSING**

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## Stages of the Ask

### I. OPENING

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

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*Advocates for Social Good & Social Justice*

RivelisSteven@gmail.com



## 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. Clear. Concise.
  - Answer questions – both asked and anticipated
  - 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”



## Stages of the Ask

### III. CLOSING

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

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## How to Shine the Light: A Movement



# Practice Session: Role Plays

### Make “The Ask” ...

- Elected Official ... to issue proclamation
- Hospital Administrator ... to secure the hospital’s involvement in your event
- Official Representative ... to light City Hall & other community landmarks in **red**

### Feedback:

- What worked?
- What could be improved?



## The Ask Practice Session:

### Elected Official ... to issue Proclamation

- > Opening
- > SIP: Situation ... Importance ... Proposal
- > Closing

Feedback: What worked? What could be improved?



## The Ask Practice Session:

# Hospital Administrator ... to secure the hospital's involvement in your event

- > Opening
  - > SIP: Situation ... Importance ... Proposal
  - > Closing
- Feedback: What worked? What could be improved?



## The Ask Practice Session:

**Official Representative ...  
to light City Hall & other community landmarks in red**

- > Opening
- > SIP: Situation ... Importance ... Proposal
- > Closing

Feedback: What worked? What could be improved?



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## Post-Poll





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## 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 [shinescdoutreach@gmail.com](mailto:shinescdoutreach@gmail.com)



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## How to Shine the Light: A Movement



**Join us for the next Peer-to-Peer learning session ...  
held on the third Wednesday of each month  
from 3:00 pm – 4:00 pm**

For information, contact Mark Goodwin at [mgoodwin@adelphi.edu](mailto:mgoodwin@adelphi.edu)



# MICHELLE

# Obama

**ONE** light feeds another.

**ONE** strong family lends strength to more.

**ONE** engaged community can ignite those around it.

This is the power of the light **WE** carry.

**Michelle Obama**

Former First Lady  
Author, *The Light We Carry*



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## How to Shine the Light: A Movement



# Shine the Light on Sickle Cell Committee - 2024

### **Chair, Shine the Light on Sickle Cell Committee – Zemoria Brandon**

SCDAA Philadelphia/Delaware Valley Chapter [PA]

### **Chair, Outreach Subcommittee – Darlene Young, Sickle Cell Association of New Jersey [NJ]**

- Barbara Harrison, Sickle Cell Association of the National Capital Area, Inc. [DC]
- Judy Anderson, Sickle Cell Association, Inc. [VA]
- Angela Mercado, Candice's Sickle Cell Fund Inc. [NY]

### **Chair, Public Relations Subcommittee – Judy Anderson, Sickle Cell Association, Inc. [VA]**

- Regina Hartfield, Sickle Cell Disease Association of America, Inc. [MD]

### **Co-Chair, Social Media Subcommittee – Murine Lusakweno-Chandler, SCDAA Philadelphia/Delaware Valley Chapter [PA]**

### **Co-Chair, Social Media Subcommittee – Isaiah Martin, Sickle Cell Association of New Jersey [NJ]**

- Teanika Hoffman, Sickle Cell Coalition of Maryland [MD]
- Sarahia Benn, Association for the Prevention of Sickle Cell Anemia, Harford and Cecil Counties, and the Eastern Shore [MD]
- Karen Byer, SiNERGe CBO Coordinator [MD]

**Social Media Consultant – Brand3, Inc. [MD]**

**Public Relations Consultant – ShinePR [PA]**



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## Resources & More

**Shine the Light webpage**

<https://wepsicklecell.org/sinerge/shine-the-light/>

**How to Make the Ask**

[https://drive.google.com/file/d/1nWOJu3JuZyjbbFUPa\\_s\\_cIAnm\\_CCvxce/view?usp=sharing](https://drive.google.com/file/d/1nWOJu3JuZyjbbFUPa_s_cIAnm_CCvxce/view?usp=sharing)

**Shine the Light Community Gathering Guide**

<https://wepsicklecell.org/sinerge/shine-the-light/#1617184229232-ed964795-4f47>

**Shine the Light Facebook Page**

[www.facebook.com/ShineTheLightOnSickleCell](http://www.facebook.com/ShineTheLightOnSickleCell)

**Contact Information**

[shinescdoutreach@gmail.com](mailto:shinescdoutreach@gmail.com)



*Thank You*

for helping to

**Shine the Light on Sickle Cell Disease**

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).