



**SiNERGe CBO ECHO – a Peer-to-Peer Learning Session on ...**

# **How to Shine the Light**



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

# How to Shine the Light: A Movement



## Shine the Light on Sickle Cell: A Movement Celebrating 7 Years





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## Pre-Poll





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**Wednesday, April 16, 2025**

**3:00 pm – 4:30 pm EST**

### **AGENDA**

- Welcome – Mark Goodwin
- Pre-Poll
- Agenda & Overview – Zemia Brandon
- Case Studies: Challenges & Successes
  - Proclamation – Judy Anderson
  - Hospital Collaboration – Mary Bentley LaMar
  - Landmark Illumination – Zemia Brandon
- How to Make “The Ask” – Steven Rivelis
- Practice Session: Role Plays – Facilitated by Zemia Brandon
- Q&A
- Post-Poll
- Resources
- Appreciations & Closure



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## Leading Today's Discussion



**Zemoria  
Brandon**

Chair, Shine the Light Steering Committee; Administrator/Social Worker, SCDAA Philadelphia - Delaware Valley Chapter



**Judy  
Anderson**

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



**Mary  
Lamar**

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



**Steven  
Rivelis**

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



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# Shine The Light – A Collaboration



SiNERGe – together with 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].



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# 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





## 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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## 2024 Highlights

42

STATES + DC + VI + PR

3K

CLICKS TO STL WEBSITE

299

MEDIA ARTICLES

185M

MEDIA AND DIGITAL ADS REACH

23

MEDIA INTERVIEWS

1.4K

META FOLLOWERS



## Hosting a Shine The Light Community Gathering





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## Case Study Interviews: Challenges & Successes

- Proclamation – Judy Anderson
- Hospital Collaboration – Mary Bentley LaMar
- Landmark Illumination – Zemoriam Brandon
- ☐ Key Tactics & Techniques



# Proclamation

Judy Anderson  
Sickle Cell Association of Norfolk



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 19<sup>th</sup> 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 19<sup>th</sup> day of June 2021.



  
**KENNETH COOPER ALEXANDER Ph.D.**  
MAYOR



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# Hospital Collaboration

Mary Bentley- LaMar

*Founder and Executive Director*

*Sickle Cell Association of New Jersey (SCANJ)*

- ✓ Leverage your partnerships
- ✓ Inventory SCD events
- ✓ Make it easy for your partners
- ✓ Show the potential impact
- ✓ Shine the Light with thanks





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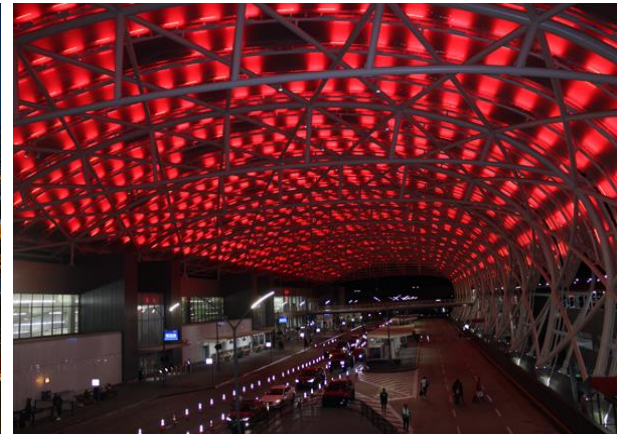
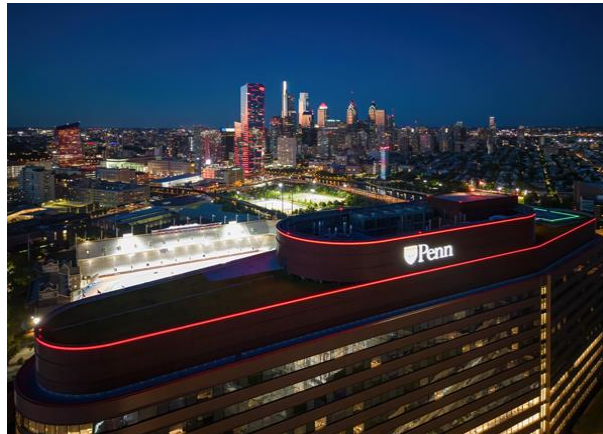
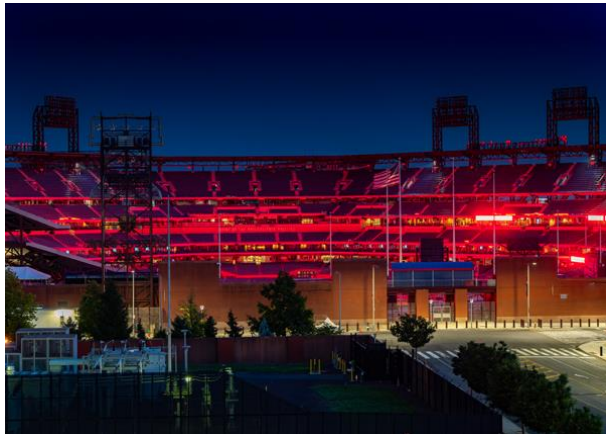
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## Landmark Illumination in Red

**Zemoria Brandon**

SCDAA Philadelphia-Delaware Valley Chapter  
Philadelphia, Pennsylvania





# How to Request Illuminating Buildings in Red

- Contact, Executive Director or Communications Director, Building and Management Owners Association (BOMA) in your area.
- Listing of BOMA locations in your area will be provided
- Send letter of request (sample template in Community Gathering Guide on page 10) to BOMA to request support from members to light up their locations on the following dates: on June 19, week/weekend prior to June 19, week/weekend after June 19, or entire month of June.
- Include STL flyer, key messages, call to action, and community gathering guide with letter of request.
- Invite BOMA to post STL information on their social media, calendar of events, and share with their network.
- Send a thank you letter to your BOMA representative after your event and invite them to support next year's STL.



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# How to make ...

# “The Ask”

Developed by: Steven Rivelis, CEO – Rivelis & Associates

*Advocates for Social Good & Social Justice*

RivelisSteven@gmail.com





## 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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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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*Advocates for Social Good & Social Justice*

RivelisSteven@gmail.com



## 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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**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)



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**There is always light.  
Only if we are brave enough to see it.  
There is always light.  
Only if we are brave enough to be it.**

- Amanda Gorman  
The Hill We Climb  
Presidential Inaugural Poem



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# Shine the Light on Sickle Cell Committee - 2025

### **Chair, Shine the Light on Sickle Cell Committee - Zemorja Brandon**

SCDAA, Philadelphia/ Delaware Valley Chapter [PA]

### **Chair, Outreach Subcommittee - Barbara Harrison, Sickle Cell Association of National Capital Area [DC]**

-Darlene Young, Sickle Cell Association of New Jersey [NJ]

-Judy Anderson, Sickle Cell Association Inc. [VA]

-Angela Mercado, Anemia Falciforme Sickle Cell Disease en Puerto Rico [PR]

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

### **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]**

-Alexandria Smith, HemoG.L.O.W.bin [DC]

-Teanika Hoffman, Sickle Cell Coalition of Maryland Inc. [MD]

-Sarahia Benn, Association for the Prevention of Sickle Cell Anemia, Hartford & Cecil Counties and the Eastern Shore [MD]

-Karen Byer, SiNERGe CBO Coordinator [MD]

### **Social Media Consultant - Brand3 Inc. [MD]**

**Public Relations Consultant - ShinePR [Philadelphia] and serving Atlanta, Boston, New York, Washington-DC, United States**



# How to Shine the Light: A Movement

## 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\\_clAnm\\_CCvxce/view?usp=sharing](https://drive.google.com/file/d/1nWOJu3JuZyjbbFUPa_s_clAnm_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).