



CELEBRATING
5 YEARS

HOSTED BY

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



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

How to Shine the Light: A Movement



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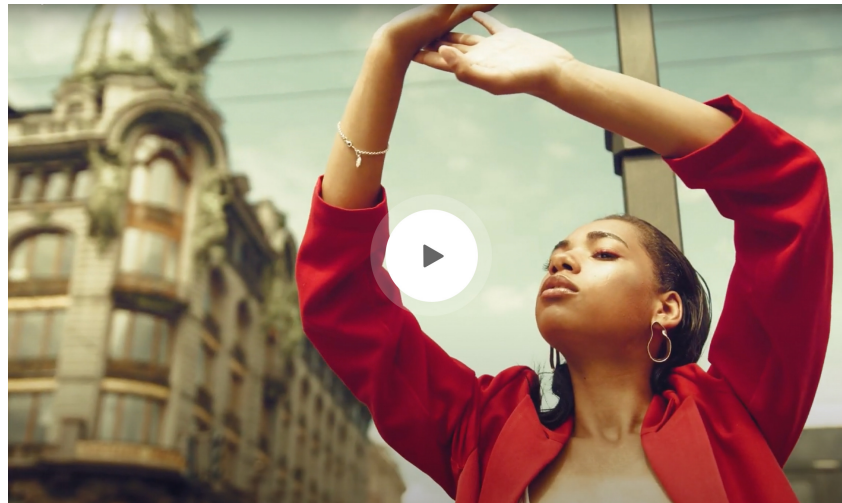
How to Shine the Light: A Movement



“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 Sub-Committee Chair
SCDAA/PDVC - Director of Programs, CHW





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Pre-Poll





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Wednesday, April 19: 3:00 pm – 4:30 pm EST

AGENDA

- Welcome – Andrea M. Matthews
- Shine the Light – Video – Murine A. Lusakweno Chandler
- Pre-Poll
- Agenda & Overview – Zemoria Brandon
- Case Studies: Challenges & Successes
 - Proclamation - Judy Anderson
 - 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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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 Sub-
Committee Chairperson;
SCDAA/PDVC, CHW



**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 –
Data Collection Lead



**Steven
Rivelis**

—
SiNERGe CBO Consultant
Rivelis & Associates, CEO



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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 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 the past five years has been so significant that the CBO leaders decided to encourage more community gatherings



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2022 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 M. Matthews
- Landmark Illumination – Zemoria Brandon
- Key Tactics & Techniques



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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 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.



K. Alexander
KENNETH COOPER ALEXANDER Ph.D.
MAYOR



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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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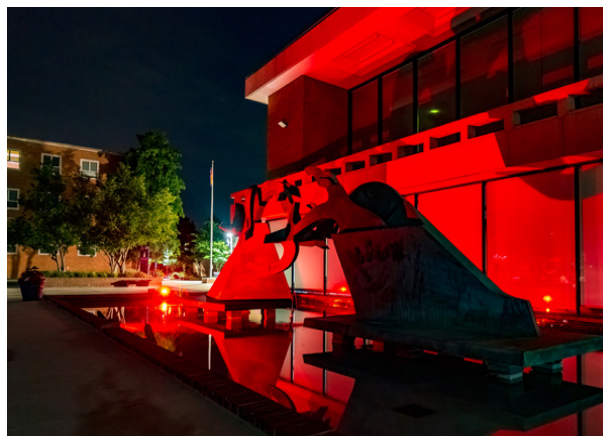
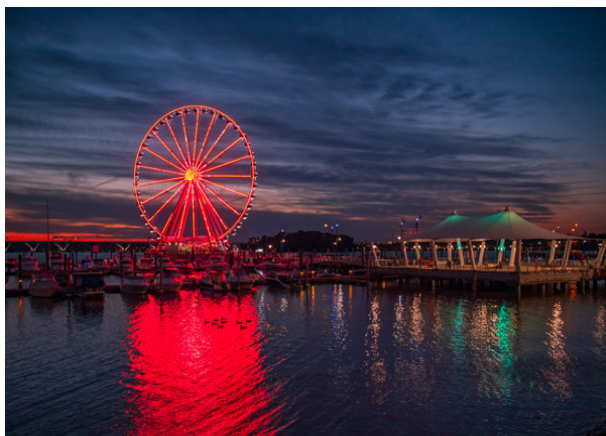
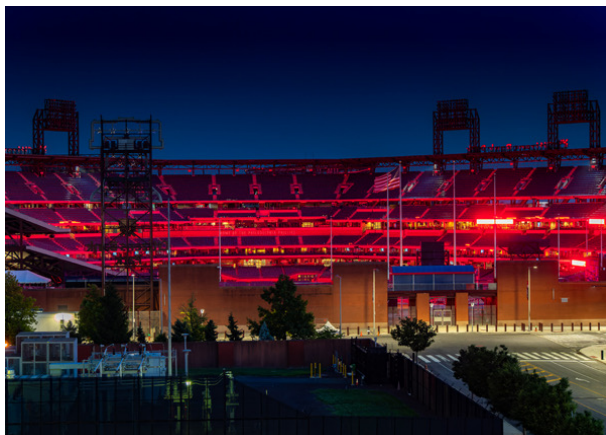
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Landmark Illumination in Red

Zemoria Brandon

SCDAA Philadelphia-Delaware Valley Chapter
Philadelphia, Pennsylvania





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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. Stages of the Ask**

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

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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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

Developed by: Steven Rivelis, CEO – Rivelis & Associates



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"



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

☐ Feedback: What worked? What could be improved?



How to Shine the Light: A Movement

The Ask Practice Session:

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

Opening

SIP: Situation ... Importance ... Proposal

Closing

☐ Feedback: What worked? What could be improved?



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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

☐ 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



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Join us for the next Peer-to-Peer learning session:

Getting Unaffiliated Patients to Care

When: Wednesday, May 17, 2023

Time: 3pm – 4pm

Overview: Panel discussion on challenges and solutions to accessing quality SCD care. Special focus on transition age of warriors and those located far from SCD clinical care.

Panelists: Dr. Wally R. Smith, Virginia Commonwealth University Health; Rudy Williams, Association of the Prevention of Sickle Cell Anemia- Harford County; Lateasha Grant-Lennon/Warrior and Mary Bentley LaMar/Moderator.



"A leader needs to know his strengths as a carpenter knows his tools, or as a physician knows the instruments at their disposal. What great leaders have in common is that each truly knows his or her strengths and can call on the right strength at the right time."

Donald Clifton



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Shine the Light - Work Group - 2023

SiNERGe Community Based Organizations' Collective Impact Initiative

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

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

Public Relations Subcommittee

Judy Anderson - *Chair, STL Public Relations Subcommittee*

Executive Director, Sickie Cell Association, Norfolk, Virginia

Public Relations Subcommittee Members –

Sarahia Benn (MD)

Outreach Subcommittee

Barbara Harrison - *Chair, STL Outreach Subcommittee*

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

Outreach Subcommittee Members –

Betty Johnson (MD), Syreeta Jones (DC), Janet Tripp (DE), Darlene Young (NJ)

Social Media Subcommittee

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

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

Social Media Subcommittee Members –

Teanika Hoffman (MD), Isaiah Martin (NJ)



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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

☐ 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

☐ Contact Information

shinescdoutreach@gmail.com



Thank You

for helping to

Shine the Light on Sickle Cell Disease
June 19, 2023

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).