



Host: Michael L. Matthews
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



We Welcome you to ... Shine the Light



A day of
community action

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





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

Leading Today's Discussion:



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



**MURINE A. LUSAKWENO
CHANDLER - SHINE THE
LIGHT STEERING
COMMITTEE, SOCIAL
MEDIA SUB-COMMITTEE
TEAM LEADER;
SCDAA/PDVC,
CHW|OUTREACH
LIAISON**



STEVEN RIVELIS
SINERGE
CONSULTANT, CEO
RIVELIS & ASSOCIATES

Pre-Poll



Shine the Light – Video

Created by:

Murine A. Lusakweno Chandler

Shine the Light Steering Committee

Social Media Sub-Committee Team Leader

SCDAA/PDVC CHW | Outreach Liaison



How to Shine the Light: A Movement

Wednesday, April 21: 3:00 pm – 4:00 pm

AGENDA

Pre-Poll

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

The Partnership Behind Shine The Light



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

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 [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 and again in 2021

Last Year's Highlights

2020 HIGHLIGHTS

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



Hosting a Shine The Light Community Gathering

Here are the are 5 steps:



Case Study Interviews: Challenges & Successes

- Proclamation - Linda
- Hospital Collaboration - Andrea
- Landmark Illumination - Zemoria
- ❑ Key Tactics & Techniques

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
findcure@aol.com
facebook.com/ArmsteadBarnhill

CS Scanned with CamScanner

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 17th day of June

Two Thousand

Lawrence J. Hogan, Jr.
Governor

Robert K. L. Loefer
Lt. Governor

John C. W. Williams
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](#)

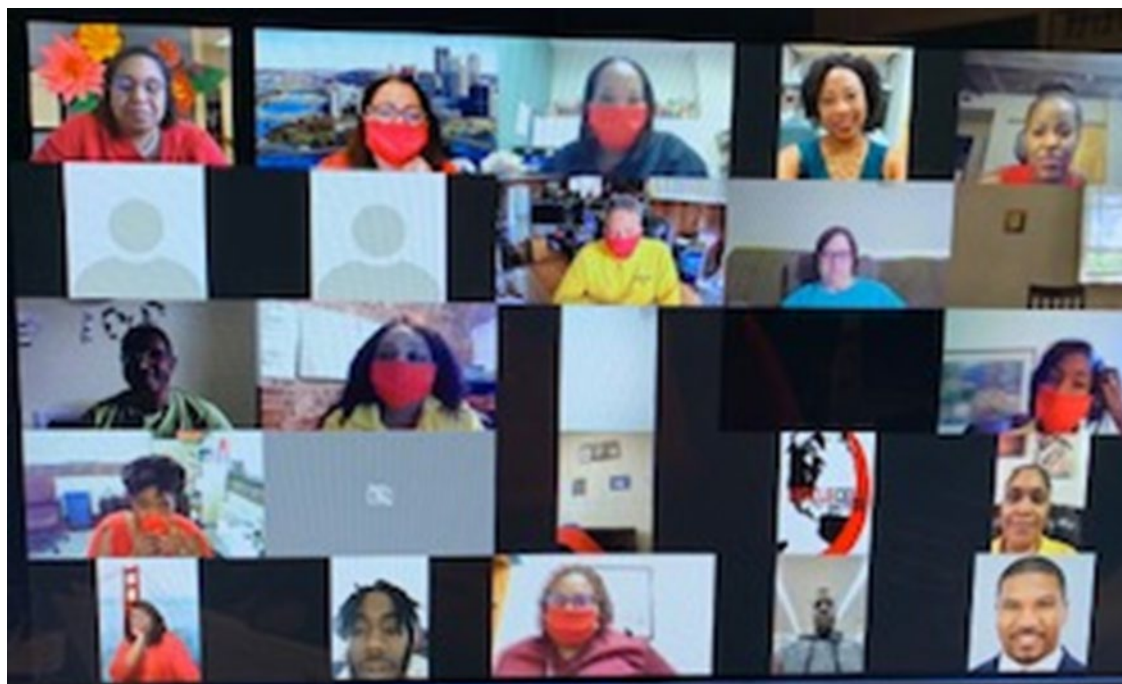
The first 100 to register before
June 12th receive a red mask for
#MasksupforSCD

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

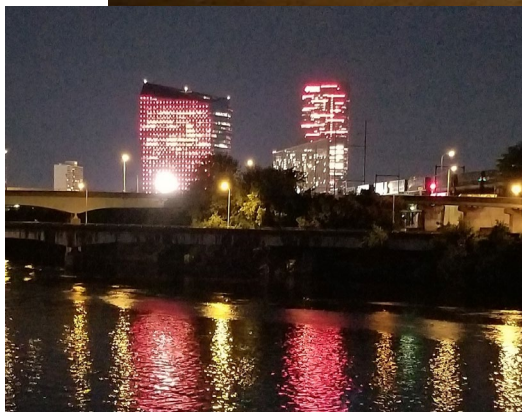
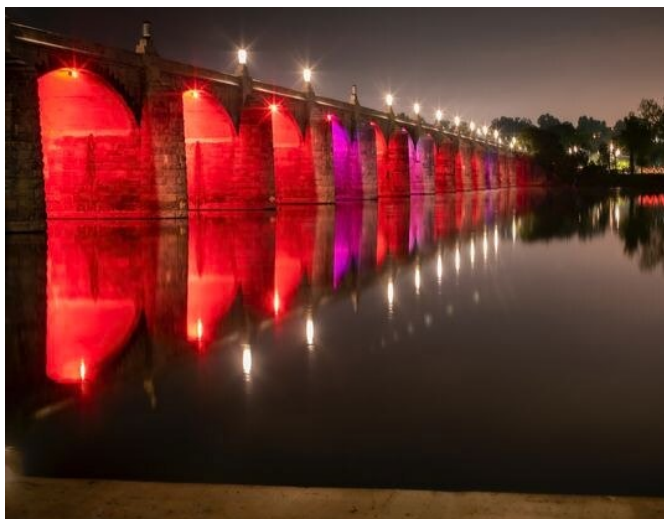


Children's
Sickle Cell
Foundation, Inc.

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



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



How to make ...

“The Ask”

The Five Knows ...

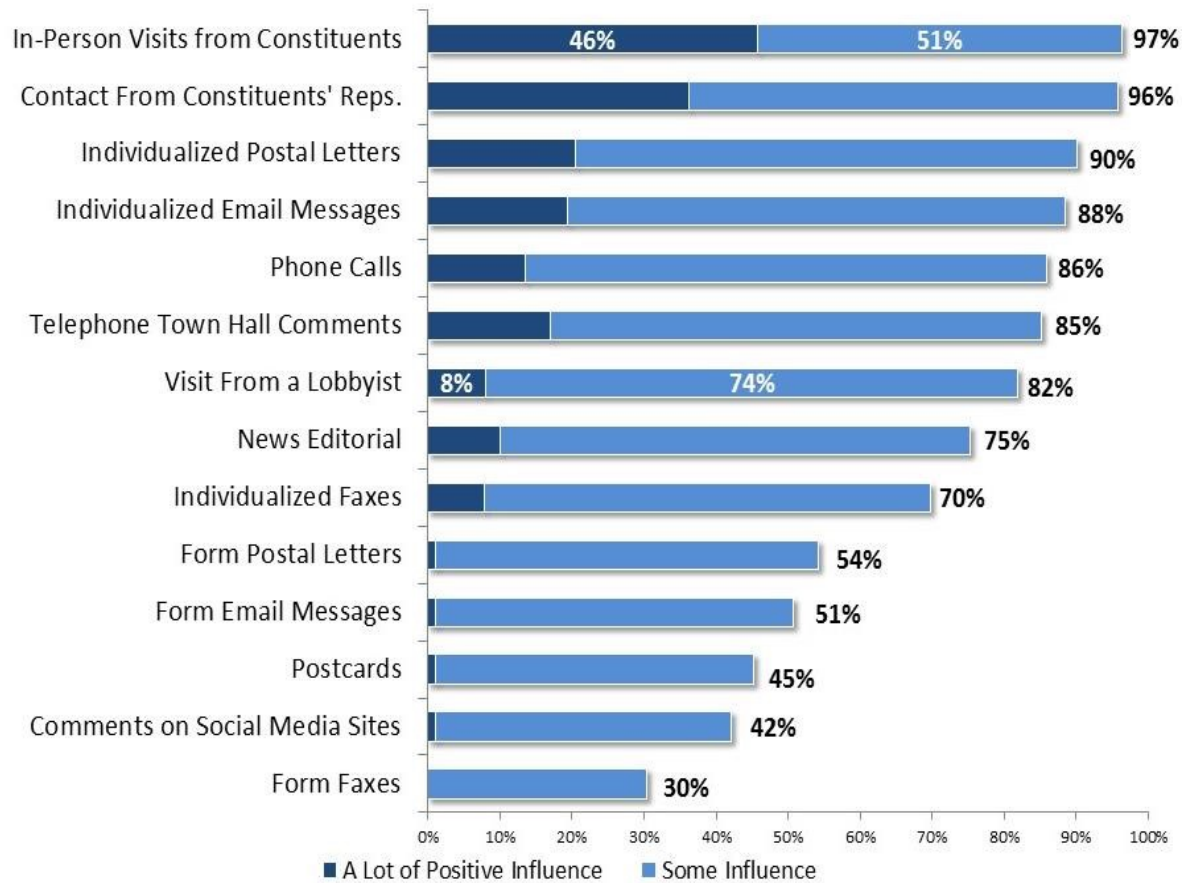
1. **Actors**
2. **Issue**
3. **Yourself**
4. **Message**
5. **The Stages of the Ask**

#1 Know the ... Actors:

Make a Connection and Build a Relationship ...

- Who are the decision makers?
- Research them ... What is their background?
- What issues are they interested in?
- What do you have in common ... What are your intersections?
- Attend their community events
- Volunteer and/or contribute
- Why might/should they be interested in this request?

Why Relationships Matter



Copyright – Congressional Management Foundation
Source – 2015 Perceptions of Citizen Advocacy

#2 Know the ... Issue:

- Convert Private/Individual Concern to Public Issue
- History
- Facts & Feelings
- Impact ... to district and general population
- Cost
- Other

#3 Know ... Yourself:

- What motivates you ... pushes your button about this issue?
- Why are you involved?
- What's your story?

#3 Know ... Yourself

Remember ... You have the ...

- Power to shape public policy & practice
- Responsibility to be active in the political arena
- Ability to influence policy/decision-makers

#4 Know the ... Message:

- Match Message to Target Audience and Presenter
- Craft Your SOCO – Single Overriding Communication Objective
- Timing is Important
- Use Facts & Feelings
- Tell Your Story - Use Words and Images – “Eye Bytes”

o

#5 Know the ... Stages of the Ask

Opening

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

The Ask: *What is the solution? How can they help?*

Closing

#5 Know the ... Stages of the Ask

Opening

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

#5 Know the ... Stages of the Ask

Case Presentation/Share Your Story:

What is the problem?

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

#5 Know the ... Stages of the Ask

The Ask:

What is the solution – How can they help?

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

#5 Know the ... Stages of the Ask

Closing

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

Practice Session: Role Plays

Make “The Ask” to ...

- Mayor/Official Representative ... to light City Hall/community landmarks
- Elected Official ... to issue proclamation
- Hospital Administrator ... to seek the hospital’s involvement in your event
- ☐ Feedback: What worked? What could be improved?

The Ask Practice Session:

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

Opening

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

The Ask: *What is the solution? How can they help?*

Closing

The Ask Practice Session: Elected Official ... to issue proclamation

Opening

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

Make the Ask: *What is the solution? How can they help?*

Closing

The Ask Practice Session:

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

Opening

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

The Ask: *What is the solution? How can they help?*

Closing

Post-Poll



Q&A

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

Resources & More

- 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
- Shine the Light Facebook Event
https://www.facebook.com/events/185715520056180/?active_tab=about

Shine the Light on Sickle Cell Disease

**World Sickle Cell Awareness Day
June 19, 2021**



Community Gathering Guide

Shine the Light - Work Group - 2021

SiNERGe Community Based Organizations' Collective Impact Initiative

Zemoria Brandon - Co-Chair, BSW, Administrator/Social Worker, Sick 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, Sick Cell Association, Norfolk, Virginia

Yvette Armstead - CEO, Armstead-Barnhill Foundation for Sick Cell Anemia

Jacqueline Baker - Founder, The Westchester Sick Cell Advocacy Network

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

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

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

Linda Howard - Member Services Coordinator, Sick Cell Disease

Association of America

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

Mary Lamar - Executive Director, Sick Cell Association of New Jersey

Meryl Lancaster - Board Member, Citizens for Quality Sick Cell Care

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

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

Crystal Rivas - Administrative Assistant, Candice's Sick Cell Fund

Shanta Robertson - Executive Director, Maryland Sick Cell Disease Association

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

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

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

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).

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

- African Proverb



Join us for the next learning session:

“Developing a Successful Community Health Worker Program”

When: Wednesday, May 19, 2021

Time: 3pm

Guest Speaker: Sabrina J. Lewis

Host: Sarai Santiago
