



SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC. (SCANCA, INC.)

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Sickle Cell Association of the National Capital Area, Inc.
is a 501 (c)(3) NONPROFIT, TAX EXEMPT ORGANIZATION

Volume 36

SPRING 2020

Education Towards the Management of Sickle Cell

MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT



Iola Y. Williams

Welcome year 2020! It is hard to believe that SCANCA, INC. was established twenty-six (26) years ago. Much has been accomplished, but there is much more needed. I am always concerned about the lack of knowledge of families and those affected with sickle cell diseases. Remember, there is very limited education about sickle cell disease given in the medical education community. Without the increased education of those affected, little will improve. It is you who must help to educate the doctors, nurses, researchers, and other medical and social caretakers. Please, check SCANCA, INC. website and any other educational materials to assist you in understanding sickle cell disease and how to best care for your body. Ask questions! Don't just sit on the sidelines. Please **GET INVOLVED**.

Thanks to all who have supported SCANCA, INC. for the past twenty-six years. Continue what you do best: support SCANCA, INC. and the sickle cell community. It can not be done without you and your participation. We **love and need you!!**

God Bless,

Iola Y. Williams, RN

Executive Director

SCANCA, INC. 2020 BOARD OF DIRECTORS Officers:

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– Secretary

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Cherrelle Esekie
Denise Garner
Barbara Harrison
Shanetta T. Richardson

SUMMER CAMP

SCANCA, INC. is working with Children's National Medical Center DC to send individuals with sickle cell to the “Braining Camp” Winchester, Virginia, for 5 or 6 days. If you are interested in your child experiencing days in a summer camp, contact Ms. Lisa Thaniel, DSW, LICSW, the Social Worker at the Children's National Medical Center at lthaniel@childrensnational.org or call her on (202) 476-3555.

EXCITING NEWS FOR SICKLE CELL ANEMIA PATIENTS

NIH launches new collaboration to develop gene-based cures for sickle cell disease and HIV on global scale

Initial investment aims to advance accessible and scalable candidate interventions into clinical trials within 10 years. (<https://www.nih.gov/news-events/news-releases/nih-launches-new-collaboration-develop-gene-based-cures-sickle-cell-disease-hiv-global-scale>).

The National Institutes of Health plans to invest at least \$100 million over the next four years toward an audacious goal: develop affordable, gene-based cures for sickle cell disease (SCD) and HIV. The Bill & Melinda Gates Foundation will also invest \$100 million toward this goal. The intention is for these cures to be made globally available, including in low-resource settings.

This initiative follows a bold announcement made earlier this year by President Donald J. Trump during the State of the Union Address to end the HIV epidemic in the United States in the next 10 years. Ending the HIV Epidemic: A Plan for America aims to leverage the powerful data and tools now available to reduce new HIV diagnoses in the United States by 75% in five years and by 90% by 2030. The Trump Administration has also elevated the attention paid to sickle cell disease, identifying it as an intractable health challenge with the potential for dramatic advances in the coming years.

Dramatic advances in genetics over the last decade have made effective gene-based treatments a reality, including new treatments for blindness and certain types of leukemia. Yet these breakthroughs are largely inaccessible to most of the world by virtue of the complexity and cost of treatment requirements, which currently limit their administration to hospitals in wealthy countries. To make these treatments effective and available for SCD and HIV, which disproportionately affect populations living in Africa or of African descent, new investment is needed to focus research on the development of curative therapies that can be delivered safely, effectively and affordably in low-resource settings.

The collaboration between the NIH and the Gates Foundation sets out a bold goal of advancing safe, effective and durable gene-based cures to clinical trials in the United States and relevant countries in sub-Saharan Africa within the next seven to 10 years. The ultimate goal is to scale and implement these treatments globally in areas hardest hit by these diseases.

“This unprecedented collaboration focuses from the get-go on access, scalability and affordability of advanced gene-based strategies for sickle cell disease and HIV to make sure everybody, everywhere has the opportunity to be cured, not just those in high-income countries,” said NIH Director Francis S. Collins, M.D., Ph.D. “We aim to go big or go home.”

The collaboration will align aggressive, high-reward research efforts to accelerate progress on shared gene-based strategies to cure SCD and HIV. Both organizations also will continue to invest in other parallel research efforts on cures for SCD and HIV outside of this collaboration.

“In recent years, gene-based treatments have been groundbreaking for rare genetic disorders and infectious diseases,” said Trevor Mundel, M.D., Ph.D., President, Global Health Program, Bill & Melinda Gates Foundation. “While these treatments are exciting, people in low- and middle-income countries do not have access to these breakthroughs. By working with the NIH and scientists across Africa, we aim to ensure these approaches will improve the lives of those most in need and bring the incredible promise of gene-based treatments to the world of public health.”

SCD and HIV are major burdens on health in low-resource communities around the world. Approximately 95% of the 38 million people living with HIV globally are in the developing world, with 67% in sub-Saharan Africa, half of whom are living untreated. Fifteen million babies will be born with

Exciting News for Sickle Cell Anemia Patients continues on page 3

Exciting News for Sickle Cell Anemia Patients continues from page 2

SCD globally over the next 30 years , with about 75% of those births occurring in sub-Saharan Africa. An estimated 50-90% of infants born with SCD in low-income countries will die before their 5th birthday and SCD is identified as the underlying cause of about 1 in 12 newborn deaths in sub-Saharan Africa.

Collaboration Details:

The collaboration will focus on two areas of coordination:

First, identify potential candidate cures for SCD and HIV for pre-clinical and clinical evaluation, co-funded by the NIH and Gates Foundation;

Second, define long-term opportunities to work together and with African partners on advancing promising candidates to late-phase clinical trials, with funding to be determined as candidates progress.

Though SCD, a genetically inherited disease, and HIV, an acquired infectious disease, present significantly different scientific challenges, gene-based treatments hold promise for both, and many of the technical challenges for gene-based cures are expected to be common to both diseases.

To achieve the goals of the collaboration, both projects will require new delivery systems that can get prospective therapies to the right places in the body and optimize treatments to target the cells involved in the respective diseases efficiently and specifically. For SCD, that would mean repairing or compensating for the mutations in hemoglobin that cause SCD in hematopoietic stem cells. For HIV, that would mean targeting the reservoir of proviral DNA that continues to lurk inside a small number of cells, even after many years of effective antiviral treatment.

Such treatments that happen entirely within the body, known as *in vivo* treatments, would be a major step forward from current treatments, which apply genetic therapies to cells taken outside the body (*ex vivo*) and then reinfused.

“We are losing too much of Africa’s future to sickle cell disease and HIV,” said Matshidiso Rebecca Moeti, M.B.B.S., Regional Director for Africa, World Health Organization. “Beating these diseases will take new thinking and long-term commitment. I’m very pleased to see the innovative collaboration announced today, which has a chance to help tackle two of Africa’s greatest public health challenges.”

SCD:

The collaboration’s goal for SCD is to develop an easy-to-administer, gene-based intervention to either correct the SCD gene mutations or promote fetal hemoglobin gene expression to achieve normal hemoglobin function. The path to a cure will rely in part on the development of gene-based delivery systems capable of selectively targeting hematopoietic stem cells. This will result in the precise correction of gene mutations or addition of a gene to promote sufficient levels of normal hemoglobin expression and function.

“Our excitement around this partnership rests not only in its ability to leverage the expertise in two organizations to reduce childhood mortality rates in low-resource countries, but to bring curative therapies for sickle cell disease and HIV to communities that have been severely burdened by these diseases for generations,” said Gary H. Gibbons, M.D., Director, National Heart, Lung, and Blood Institute (NHLBI), part of the NIH. “A person’s health should not be limited by their geographic location, whether rural America or sub-Saharan Africa; harnessing the power of science is needed to transcend borders to improve health for all.”

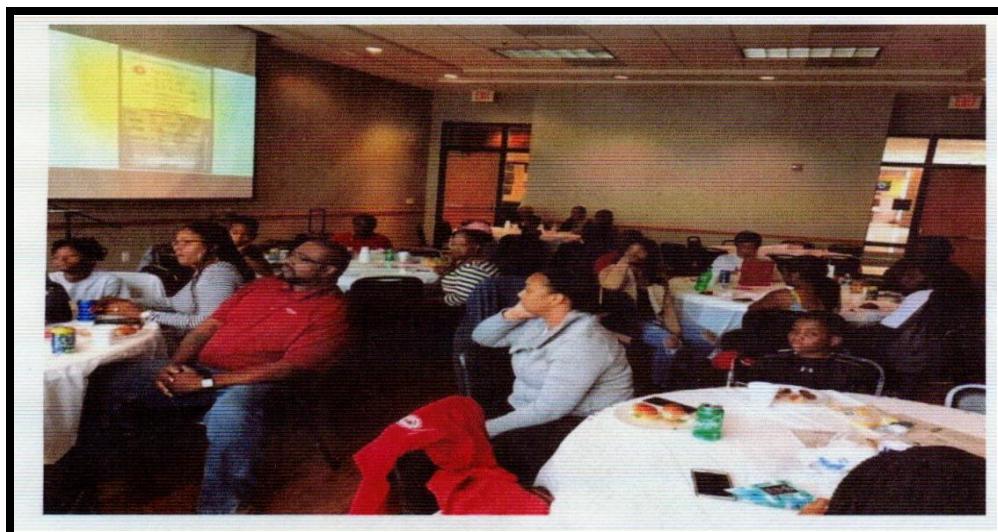
In addition, more needs to be done to understand the burden of SCD in sub-Saharan Africa and to screen newborns for SCD in high-risk geographic areas. NHLBI has already begun to establish a clinical research infrastructure in sub-Saharan Africa. However, additional clinical research and capacity-building efforts are needed to deliver point-of-care screening, such as at the time of infant vaccinations, and to initiate a standard of care. These activities will be undertaken by NIH and Gates Foundation outside of the collaboration, but will support collaboration efforts.

NOTE: The preceding article is an excerpt from the Sickle Cell News for November 2019 by Allan Platt and staff of the Emory University. View the complete article at the website: <https://www.nih.gov/news-releases/nih-launches-new-collaboration-develop-gene-based-cures-sickle-cell-disease-hiv-global-scale>

SICKLE CELL SUPPORT GROUP KICKOFF EVENT
Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.)

The Sickle Cell Association of the National Capital Area, Inc. SCANCA, INC. Support Group Kickoff was held on October 5, 2019 at The Arc, 1901 Mississippi Avenue S.E., Washington, DC 20020. The event was designed to inform the community about the start of the Sickle Cell Disease support group that will serve the DMV area. The SCANCA, INC. coordinators are Ms. Shanetta Richardson and Mrs. Barbara Harrison.

This Kickoff was a success. The event started with an ice breaker bingo game, which allowed everyone to meet and interact with each other. SCANCA, INC. provided lunch, catered by MLK Deli of DC., to everyone. SCANCA, INC. also distributed a bag of items with the SCANCA, INC. logo to everyone in attendance. We also handed out gifts bags and coloring pages and activities to sickle cell disease (SCD) individuals while the event was taking place.



In order to increase the number of people who are able to participate, the support group sometimes meets online. All you need is a phone, tablet, laptop or computer to log in and join the conversation! See below for all the details. We hope to see you at an upcoming meeting in March or April. Without you, the group cannot exist!

March 28, 2020 – 12:00 noon – 1:00 PM
Deanwood Community Center, 1350 – 49th Street, NE, Washington, DC 20019
Conveniently located near Deanwood Metro Station
We will work on VISION BOARDS! It's time to see your future with 2020 vision!

April 25, 2020 – Videoconference – 12:00 noon – 1:00 PM

Download the ZOOM app!

Click on this link <https://zoom.us/i/2234556677>

Meeting ID: 223 455 6677

OR, to join us by phone (no video): 646-558-8656, Meeting IDL 223 455 6677

SCANCA, INC. CONGRATULATES OUR 2019 SCHOLARSHIP AWARDEES

Ms. Kaitlyn Adams



Desires to be a Social Worker

Ms. Erica Quan



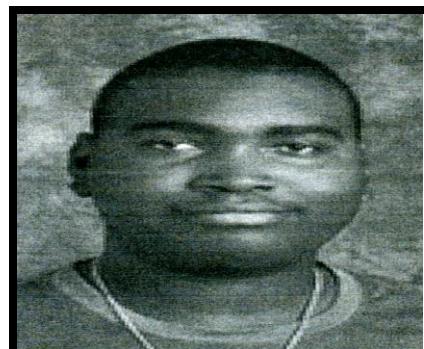
Desires to be a physician

Mr. Xavier Ray



Desires to be a Software Engineer

Mr. Quentin Vickers



Desires to be an
Astronautical Engineer

JOIN THE MARROW REGISTRY

BE  THE MATCH

Bone marrow transplants may free sickle cell sufferers from the pain of the disease. Potential donors must be between the ages of 18 and 60, be willing to donate to any patient in need, and meet the health guidelines.

A cheek swab is all it takes to see if you are a match to help save the PRECIOUS GIFT OF LIFE.

**For info, call: 800-MARROW2
OR go to the website: BETHEMATCH.ORG**

2019 Holiday Party



SCANCA, INC'S members and the Sickle Cell Community had a wonderful time with all of the trimmings

We should all congratulate the SCANCA, INC. team on another successful holiday party! Everyone ate well, and the kids were happy with their gifts. Of the 23 families who RSVP'd, 14 showed up. Another three families registered onsite, and we had few adults with sickle cell disease who also joined us.

Santa also looked especially happy and thankful to be there! The Santa suit is ready for next year. Hats off to Ms. Adrienne Romain, the daughter of Denise Garner a member of SCANCA, INC. Board of Directors, who made a wonderful Mistress of Ceremonies.

You must stay tuned to SCANCA, INC. website (www.scancainc.org) for the December 2020 holiday celebration.

Sickle Cell Disease Association of America, Inc. Peer Mentoring Training Program

"Where Leadership and Patient Advocacy Meet"

Program Goal

The goal of the program is to give support to those individuals who are completing the transitional phase from pediatrics to adult care. It will consist of 1-on-1 phone calls and/or text messages that will focus on healthy living with sickle cell disease. The program will use the web-based Mentor1to1™ platform and PeerMentor™ smartphone app.

Mentee Eligibility

The Peer-to-Peer Mentoring Program is currently available to anyone needing support and education in successfully transitioning into adult sickle cell health services.

1. Must be 18 years or older
2. Have a high school diploma, equivalent or higher
3. Have a valid government issued ID
4. Complete application requirements
5. Must be diagnosed with sickle cell disease
6. Must be transitioning to adult care
7. Must have a daily/regular phone (residence or a cellular line) that can be used to make mentoring phone calls
8. Must have daily/regular access to a computer, tablet, or laptop with internet access

**For more information please contact the Community Engagement Manager Shantia Fitzgerald at
sfitzgerald@sicklecelldisease.org or by phone at 410-528-1555**

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) grant number U38MC28326. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

HEALTH TIPS

Warm weather is coming!!! Please take care of your health.

Some items to remember are:

1. Always carry a light jacket or sweater, no matter how warm it seems, to wear in cool atmosphere (with air conditioning.);
2. Do not swim in cold water and always have a towel to dry off immediately;
3. Water is important. Drink!!! Confer with your medical caretaker especially if you have complications;
4. Always practice slow deep breathing. Inhale through your nose and exhale through your mouth;
5. If you are traveling, ask your medical caretaker if there should be any precautions.

HAVE A GREAT SPRING AND SUMMER

SUPPORT THE SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC. (SCANCA, INC.)

Please mail your financial support to:

SCANCA, INC.
P. O. Box 41479
Washington, D. C. 20018-0879
OR

Send donations through Paypal.com to: email@scancainc.org

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501 (c)(3) NONPROFIT, TAX EXEMPT ORGANIZATION

One Year Membership Dues: \$25.00 _____ Organizations/Corporations: \$100.00

_____ Scholarship Donation _____ Other Donation Amount: \$_____

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Phone Number: Home- (_____) _____ Work- (_____) _____

E-Mail: _____ Cell phone: _____

Do you have a family member(s) with Sickle Cell Disease? _____ Yes _____ No

UPCOMING EVENTS – 2020

March 28, 2020 – 12:00 noon – 1:00 PM – Deanwood Community Center – [SEE PAGE 4, SUPPORT GROUP](#)

April 20-21, 2020, SCDA NATIONAL SICKLE CELL ADVOCACY DAY 2020 with focus on key legislative issues.
Location: Gallaudet University, 800 Florida Avenue, NE, Washington, DC 20002.

Coordinator: Natasha Thomas Phone: 410-528-1555, email: NThomas@sicklecelldisease.org.

April 25, 2020, 12 noon – 1:00 PM - [SEE PAGE 4, SUPPORT GROUP](#).

May 2, 2020, 12 Noon to 2 PM - SCANCA INC. SPRING WORKSHOP/SUPPORT GROUP FINALE.

“NEW MEDICATIONS FOR SICKLE CELL DISEASE: WHAT’S THE REAL STORY?”

Guest Speaker: Patricia Oneal, MD. - 8400 Corporate Drive, Landover, MD 20785 - (First floor meeting room, in rear of building) Luncheon included - **RESERVATION NEEDED BY APRIL 29, 2020: RSVP@SCANCAINC.ORG or (301) 883-1362. FREE!!**

June 19, 2020, WORLD SICKLE CELL AWARENESS DAY

Location: National Harbor, Oxon Hill, Maryland. Check SCANCA, INC. website at: www.scancainc.org for more details.

July 11, 2020, SCDA WALK WITH THE STARS AND MOVE-A-THON

Location: Canton Waterfront Park, Baltimore, MD.

Contact: SCDA 410-528-1555, Toll Free: 1-800-421-8453. Web: <http://www.sicklecelldisease.org>

October 13 – 17, 2020 - Sickle Cell Disease Association of America, Inc. (SCDA, INC.)

National Convention --The Rosen Centre, 9840 International Drive, Orlando, FL 32819

SCDA 410-528-1555, Toll Free: 1-800-421-8453,

Web: <http://www.sicklecelldisease.org>, -- email: admin@sicklecelldisease.org

SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING

By Appointment Only

Contact: SCANCA, INC. Office – 202-271-5733

SCANCA INC. Executive business meeting

For information call : SCANCA, INC. Office



**P.O. BOX 41479
WASHINGTON, DC. 20018-0879**

**Sickle Cell Association of the National Capital Area, Inc.
(SCANCA, INC.)**



Education Towards The Management of Sickle Cell

**2020 Scholarship Application
Five Hundred Dollar (\$500.00) Scholarship
DEADLINE: JUNE 30, 2020**

Type or Print Applicant's Name _____ Date of Birth _____

Address _____

City _____ State _____ Zip Code _____

Telephone # () _____ Email Address _____

School or College Attending: _____

Address of School _____

City/State/ Zip Code _____ Telephone # _____

Course of Study (current students): _____

Number of Years completed _____

(previous recipients may reapply – SCANCA, INC. Board decisions are final)

ALL APPLICATION PACKAGES MUST BE TIMELY AND COMPLETE

Attach the following:

1. Letter from doctor/nurse or social worker verifying Sickle Cell Disease;
2. Graduating High School Senior or College /Technical Student letter of acceptance from a prospective post high school;
3. Copy of transcript with GPA of 2.5 or more;
4. Two (2) letters of recommendation (one from community and one from school official);
5. An essay (minimum of 500 words) describing your goals and aspirations with applicant's signature and a recent photo. (All photos are subject to publication in SCANCA, INC. newsletter.)

Applicant must be a resident of the Washington, D.C. Metropolitan Area (Md., DC., VA.)

The 2020 application deadline is June 30, 2020. All documents must be enclosed and received by the deadline.

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SEPTEMBER IS NATIONAL SICKLE CELL MONTH
