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 35 FALL 2019

Education Towards the Management of Sickle Cell

1ST PLACE

TWENTY-FIVE YEARS OLD

CONGRATULATIONS

MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT

Iola Y. Williams

Hello Friends: What a blessing it is for The Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.) to celebrate our TWENTY-FIFTH ANNIVERSARY. Time seems to have sped pass as we provide needed services to our sickle cell families and the community-at-large.

The services we provide consist of educational, benevolence, research, collaborative medical and social intervention, and many more. Our educational services include: workshops, health fairs, symposiums, counseling, interagency collaboration for client benefit, scholarships, newsletters and other written materials, and an in-depth web site which we encourage you to view. Our benevolence services include: partial or full financial assistance with general financial distress – scholarships, utilities, funerals/burials, rental/mortgage delinquency, and medical supplies/bills. These are just a few of the services we provide.

Legally, SCANCA, INC. must meet many requirements, though sometimes trying. We must comply with rules of IRS to qualify for our nonprofit 501(c)(3) tax exempt status for the Federal Department of the Treasury and the District of Columbia, annual confirmation and payment of Trade Name Status through the DC Government Corporation Division, and the Annual Basic Business License through the Department of Consumer and Regulatory Affairs of the District of Columbia.

Our dedicated Board of Directors is a volunteer group (no one is salaried). Your donations and gifts are what help us to maintain our promise of service. There is much to be done continually. I must thank our Board of Directors which maintains some sanity in our programs. We thank all of you and want you to know that we need your continual support in this journey. God bless you!

Iola Y. Williams

Executive Director

SEPTEMBER IS NATIONAL SICKLE CELL AWARENESS MONTH

AN OVERVIEW

Roland B. Scott Symposium

"Preparing the Next Generation of Advocates for Sickle Cell Disease Care"

May 7, 2019, Howard University Hospital, Washington, DC

Pictured – SCANCA, INC. representatives: Oceola Briscoe, Denise Garner, Shanetta Richardson*, Iola Williams*, Beverly Ames and Barbara Harrison*(*- SCANCA, INC. awardees)

Pictured :
Group of National Awardees at the Roland B. Scott Symposium

A great day of celebration, appreciation and sharing of experiences and information of future studies and projected cures were shared. It was well attended including speakers representing Cystic Fibrosis Foundation, Sickle Cell Disease Association of America, and Campaign Consultation, Inc. Three Lifetime Achievement and Sixteen Outstanding Service Awards were given to deserving individuals. Three Board members of SCANCA, INC. were amongst the recipients: Ms. Iola Williams, Mrs. Barbara Harrison and Ms. Shanetta Richardson. We congratulate you and appreciate all that is done for SCANCA, INC. and the sickle cell community. Also, thanks to Mr. Tyrone Briscoe who manned SCANCA, INC. table while our members sat in on the celebration.

Another outstanding moment was, on Sunday, May 5, 2019, when our Executive Director/President was recognized at Zion Baptist Church in celebration of "Women in Leadership." "**CHEERS**!!"

Health Fair at Fort Belvoir

Board members, Shanetta Richardson and Oceola Briscoe represented SCANCA, INC. at Fort Belvoir's 2019 Health and Safety Expo on May 14, 2019.

Exciting News for Pediatric Sickle Cell Anemia Patients

Medunik USA, a company dedicated to improving the health and quality of life of Americans with rare diseases, is proud to announce the launch of Siklos® (hydroxyurea). Siklos® is indicated to reduce the frequency of painful crises and the need for blood transfusions in pediatric patients two years of age and older with sickle cell anemia with recurrent moderate to severe painful crises. Siklos® is the first and only FDA-approved hydroxyurea-based treatment for use in pediatric patients with sickle cell anemia.[1] It is not known if Siklos® is safe and effective in children less than 2 years of age.

Siklos® is an important new treatment option for patients with sickle cell anemia (SCA). As we know, despite initial identification of this disorder over one century ago, SCA continues to represent a major health challenge in the U.S. affecting nearly 100,000 Americans, decreasing life expectancy by as many as 25 to 30 years, and significantly impacting the quality of life of those afflicted.[2,3]

“This approval is a major milestone in treatment for all children who suffer from devastating pain and disability associated with sickle cell anemia,” said Abbey Meyers, founder and past-president of the National Organization for Rare Disorders (NORD) and member of Medunik’s Advisory Board.

FDA approval for Siklos® was granted based on tolerability and effectiveness data collected in a European sickle cell disease cohort (Escort-HU) study, which included 405 pediatric patients. Data showed that treatment with Siklos® increased the concentration of fetal hemoglobin (hemoglobin F or HbF), which prevents the sickling process in red blood cells. In the clinical trial, the number of pediatric patients who experienced at least one painful crisis in the 12 months prior to treatment with Siklos® was significantly reduced after 12 months of treatment.[1]

Siklos® is available by prescription as 100-mg oral tablets, which, when taken under a doctor’s care, are designed to offer flexible dosing based on a patient’s weight and maximum tolerated dose. This is particularly important in the pediatric population, where patient weight is constantly changing. Siklos® is dissolvable in water for oral administration to patients who have difficulty swallowing tablets whole.

Healthcare providers, patients and caregivers can read more about Siklos® in the full Prescribing Information, including **Boxed Warning**, the patient Medication Guide and Instructions for Use.

Siklos® will have dedicated affordability and assistance programs for patients in need.

Should you have any questions about Siklos®, please contact Medunik USA at 1 844-633-8645 or visit www.medunikusa.com.

Medunik USA, Inc. | Rosemont, PA 19010

Toll Free: 844.633.8645 | Fax: 267.428.1809

Stay up to date on Siklos®

To receive news and updates regarding Siklos®, subscribe to our communication list.

Please see Important Safety information, including **Boxed Warning**, as follows.

About SIKLOS® (hydroxyurea)

Siklos® is a prescription medicine that is used to reduce the frequency of painful crises and reduce the need for blood transfusions in children, 2 years of age and older, with sickle cell anemia with recurrent moderate to severe painful crises. It is not known if Siklos® is safe and effective in children less than 2 years of age.

World Sickle Cell Day Symposium in recognition of 10th Anniversary of Sickle Cell Day
Howard University Hospital - Wednesday, June 19, 2019

SCANCA, INC. representatives were:
Beverly Ames, Barbara Harrison and Oceola Briscoe

Rapid Result Test On Track to Transform Sickle Cell Disease Screening for Millions

Soon after birth, a baby in the United States is tested for sickle cell disease, the often-devastating genetic blood disorder affecting more than 100,000 Americans and 20 million of people worldwide. If positive, that newborn typically begins a course of treatment that can greatly prolong life and help stave off complications of the disease.

Now, research shows that with a new rapid result test kit, a diagnosis of sickle cell disease may no longer be a death sentence for children in the most affected parts of the world (Africa).

HemoTypeSC, a dipstick-type test, is relatively inexpensive, accurate, and can provide timely diagnosis of sickle cell disease, according to the study external link published in the American Journal of Hematology. The test has the potential to be a game-changer for people with the disease who live in distressed areas around the world.

"Children with sickle cell disease have down to a 10 percent chance of reaching their fifth birthday if they are not diagnosed and get treatment early in life," said Erik Serrao, Ph.D., a study author who also is the HemoTypeSC project manager at Silver Lake Research Corporation, the Los Angeles-based diagnostic company that developed the test. "That is why it's extremely important to screen for the disease at birth or within the first year of life."

Current gold-standard clinical methods for diagnosing sickle cell disease require laboratory equipment, a continuous electrical supply, a dedicated operating staff, about 1 mL of whole blood from each patient, and the ability to transport blood samples from where they were collected to possibly distant testing facilities.

HemoTypeSC uses simple technology—test strips—similar to a pregnancy test. The strips contain specific proteins that, in a few simple steps and after a short waiting period, can detect normal and abnormal hemoglobin proteins in whole blood.

In sickle cell disease, abnormal hemoglobin proteins cannot deliver oxygen to the body's tissues due to defective hemoglobin S and C genes. The end results are sickled shape red blood cells and a cascade of complications such as sudden, severe pain known as pain crises.

The test can also detect the sickle cell trait, which shows up in someone who inherits one hemoglobin S or C and one normal hemoglobin A gene. While the sickle cell trait typically does not result in symptoms or complications from the disease, it is important for couples who are planning to have children to speak with a health professional who can explain the risk of having a child with sickle cell disease. The test does not require sophisticated laboratory equipment, electricity, refrigeration, or highly trained personnel.

To evaluate its effectiveness, the team tested HemoTypeSC in study centers in Techiman, Ghana; in Martinique, part of the Caribbean Islands; and in Cincinnati, OH. Using a single drop of blood from each of the 587 participants—newborns, children, and adults across the three centers—the HemoTypeSC test correctly identified those with and without sickle cell disease and sickle cell trait in almost all of the cases.

Serrao acknowledged that one limitation of HemoTypeSC is its inability to detect hemoglobin D, E, and O, which are common in some parts of the Middle East and Southeast Asia.

Meanwhile, Serrao said he and his colleagues are focused on bringing HemoTypeSC to as many people as possible, including those living in Europe and its territories, where the test is already approved (Kenya, Nigeria, Uganda, India and other African countries).

The test was recently approved in Nigeria, Ghana, Uganda, India and in other African countries. In the United States, where Serrao said the test could be helpful at blood banks that need to screen new and archived blood samples, HemoTypeSC is awaiting approval.

"HemoTypeSC can help both children and adults afflicted with sickle cell disease," Serrao said. "Once these young people are identified with the disease, they can be put on medication and become healthy, happy, and extremely productive members of society." in the United States, where Serrao said the test could be helpful at blood banks that need to screen new and archived blood samples, HemoTypeSC is awaiting approval.

Complete article—

https://www.nhlbi.nih.gov/news/2019/rapid-result-test-track-transform-sickle-cell-disease-screening-millions

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ASSISTANCE IS ALWAYS APPRECIATED

SCANCA, INC. is grateful to Ms. Shanetta Richardson and Ms. Barbara Parker Tripplett for their support in the mailing of the SCANCA, INC. Newsletters. Once the newsletters were delivered Ms. Richardson (our newest Board member) and Ms. Tripplett came to the editor's home to work addressing and stamping envelopes for mailing. Thanks so much for your support in this effort.

SCANCA, INC. 2019 SCHOLARSHIP AWARDEES

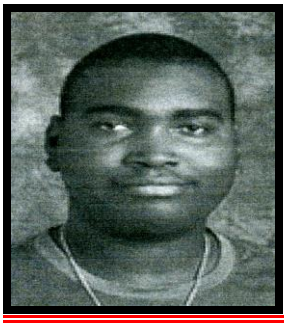
SCANCA INC's mission is to enhance the education of persons with sickle cell disease. This is done by providing scholarships to students enrolled in institutions of higher learning (e.g.: college, technical school or graduate school).

In 2019, SCANCA, INC. will award four (4) scholarships of $500 each to applicants - all of whom are high school seniors in their respective schools. Each of the candidates has faced a challenging course with their medical conditions, yet all have remained determined not to allow their medical situation to determine the direction of their lives. The candidates faced adversity with optimism and a "can do" spirit.while not always able to attend school, they view education as a stepping stone to their future and maintained a strong desire to excel academically.

Kaitlyn Adams has developed strong personal skills and qualities such as perseverance, self-awareness and efficiency. She states that she has managed to learn how to push past her pain and work hard every day to stay ahead of classes. She believes that she puts much effort into every task given her. She gives only her best and will do everything in her power to achieve and know that she is doing her best. Her desire is to become a Social Worker.

Erica Quan is an aspiring female physician who believes she is a confident, strong-willed leader. She wants to be better with each yesterday and is driven by dreams of helping people around the world through the study of biomedical sciences and the skills of research. Ms. Quan will be applying to medical school this time next year and be taking the ultimate steps towards her goal. The skills and experiences accumulated over the last four years will show schools that she has what it takes because she will take advantage of the opportunities to become the best physician she knows that she is capable of achieving.

Xavier Ray will be a senior at Morgan State University in the Fall of 2019. He has been inspired by working in programs to increase the participation rates for people with disabilities in mission related occupations. He presents with multiple recommendations from his past educational and social encounters. He has tried working in capacities as a Software Engineer and a Forensic Lab Technician. Mr. Ray continues to seek different avenues of experiences to discover a satisfying career as he finishes his college courses.



Quentin Vickers is aspired to observe what is in the world to the point of how it works. He has learned a variety of real-life components to use in designing his own craft and the endless designs that can be made from it. His desire is to be in Astronautical Engineering in a place that designs and builds spacecraft. He is motivated everyday to keep up his hard work in making sure that he can not only make it through college, but also make an amazing and successful career for himself.

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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SCANCA, INC. IS NO LONGER ASSOCIATED WITH CFC

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

SCANCA, INC. SUPPORT GROUP IS BEING REFORMATTED

STAY TUNED FOR MORE DETAILS …. www.scancainc.org

Let us know if you would like to assist in this effort - THANKS

UPCOMING EVENTS – 2019/2020

SOS MOVE-ON-EVENT
September 21, 2019
Howard University Hospital
2041 Georgia Avenue, NW -
Washington, DC 20060
Contact: amason@howard.edu

Sickle Cell Disease Association of America, Inc. (SCDAA, INC.)
National Convention - Saturday, October 9 – 12, 2019
Renaissance Baltimore Harborplace
202 E. Pratt Street – Baltimore, Maryland 21202
Contact/Information: Office – 410-528-1555
Web: www.sicklecelldisease.org
Toll Free: 1-800-421-8453
Email: admin@sicklecelldisease.org

SCANCA, INC. ANNUAL HOLIDAY CELEBRATION
Saturday, December 7, 2019
11:30 am – 3:00 pm
8400 Corporate Drive, Landover, Maryland 20785
RESERVATION NEEDED: rsvp@scancainc.org

SCANCA, INC. SPRING WORKSHOP
Saturday, May 2, 2020 - luncheon included
12 noon – 3pm
8400 Corporate Drive - Landover, Md. 20785
(first floor meeting room – in rear of building
RESERVATIONS NEEDED – rsvp@ scancainc.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

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