



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

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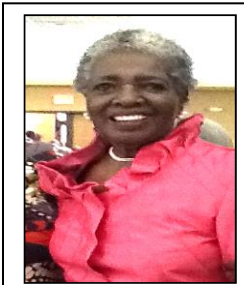
*Sickle Cell Association of the National Capital Area, Inc.
is a 501 (c)(3) NONPROFIT, TAX EXEMPT ORGANIZATION*

Volume 34

SPRING 2019

Education Towards the Management of Sickle Cell

MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT



Iola Y. Williams

Hello Friends:

The Board of Directors of the Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.) THANKS YOU for your generous support over the years. We hope that our programs and services have inspired you and that we can continue. In all issues of our newsletter we try to show how your support serves the community at large as well as the Sickle Cell Community.

You have touched many lives with your assistance in furthering education about this often devastating genetic disorder as well as participation in research, preventive health maintenance, early detection and treatment of complications. Many families are supported and helped through our patient/family services and programs funded through your giving.

Again, we thank you! We need you! Together we can continue to educate as we support, prolong, and save lives. Please see our web site: www.scancainc.org.

**SEPTEMBER IS NATIONAL SICKLE CELL
AWARENESS MONTH**

**SCANCA, INC. 2018
BOARD OF DIRECTORS**

Officers:

**Iola Y. Williams, RN. –
Exec. Director/President**

**Cathy McCoy
– Vice President**

**Beverly Ames
– Secretary**

**Lorenzo Nichols, Jr.
– Treasurer**

At-Large Board Members:

**Oceola Y. Briscoe - Editor
Cherrelle Esekie
Denise Garner
Barbara Harrison
Shanetta T. Richardson
Madline Morsha-Taylor**

ASSISTANCE IS ALWAYS APPRECIATED

SCANCA, INC. is grateful to Mr. Tyrone Briscoe and Ms. Madline Morsha-Taylor, (our Chaplain) for their support of the organization. Once the newsletters were delivered Mr. Briscoe and Ms. Taylor got to work addressing and stamping them for mailing. Mr. Briscoe even took the packages to the post office. Thanks so much for your support in this effort.



SCANCA, INC. WELCOMES SHANETTA TEAL RICHARDSON TO ITS BOARD OF DIRECTORS



Ms. Shanetta T. Richardson was diagnosed with (SS) Sickle Cell Anemia Disease at birth. She has the type of Sickle Cell that is caused by a mutation in the blood cell protein called hemoglobin. Due to the complications of Sickle Cell Anemia disease, Ms. Richardson could not attend school regularly. However, because of her persistence & determination, she obtained her G.E.D. while being confined to a hospital bed, in the fall of 1999. While dealing with this disease, Ms. Richardson obtained her Bachelor's Degree in Business Administration with the Concentration in Management with a Minor in Human Resources Management in 2018 from Strayer University.

Ms. Richardson has spent most of her life in the hospital and celebrated every holiday in the hospital. Even though she has suffered her entire life from Sickle Cell Anemia disease with pain crisis, brain tumor and being temporarily paralyzed amongst other setbacks, she has always kept God first. She always encourages and uplifts others in spite of what she is going through.

Shanetta T. Richardson is a mother of three beautiful young ladies and the proud grandmother of two. She loves God more than life and is spiritual, confident, bold and resilient. She loves hard. She is a go-getter who refuses to quit even when disappointed. She cries real tears and feels real pain. Sometimes she feels wounded but never DEFEATED and that causes her to bounce back because of her Great faith. Through it all, she is still present with a pure heart and bold presence. She laughs and smiles and continues to LIVE. Don't discount her because of where she appears to be because where she is going is UNIMAGINABLE!!! Shanetta lives by the motto: "Sickle Cell Don't Control Me, I Control IT!"

Ms. Richardson expresses her interest in working with SCANCA, INC. The SCANCA, INC. board members welcome Ms. Richardson and look forward to doing great things together.

SICKLE CELL NEWS

<http://scinfo.org/newsletter/>

These Patients Had Sickle-Cell Disease. Experimental Therapies Might Have Cured Them.

Success against sickle-cell would be "the first genetic cure of a common genetic disease" and could free tens of thousands of Americans from agonizing pain.

<https://www.nytimes.com/2019/01/27/health/sickle-cell-gene-therapy.html>

Carmen Duncan, 20, of Charleston, S.C., had her spleen removed when she was 2, a result of complications from sickle-cell disease. She spent much of her childhood in and out of hospitals.

"Sometimes I would stay two weeks," she said. Her arms and legs would ache from blocked blood vessels. "A simple touch really hurt."

Monthly blood transfusions helped, she said, but they were onerous. Then she entered Bluebird's gene therapy trial.

Today, doctors say, she no longer has signs of sickle-cell disease. She had longed to join the military but had been barred because of her condition. Now she plans to enlist.

Manny Johnson, 21, was the first patient in a trial at Boston Children's Hospital in which researchers are attempting to restart production of fetal hemoglobin. It worked: Doctors say he no longer has the disease.

SUMMER CAMP – NOW IS THE TIME TO THINK ABOUT SUMMER CAMP – LET YOUR SOCIAL WORKER KNOW AND HAVE HIM/HER CONTACT SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC. (SCANCA,INC.)

TRANSITION IS AN IMPORTANT PROCESS

- You may not be able to keep your current doctors after a certain age;
- Prepare early so you can still involve your pediatric doctors during the transition process;
- If you plan higher education, look for scholarships for individuals with sickle cell disease. Both medical and financial resources are available.

Adult care centers are very different from pediatric offices. The biggest change is often the amount of input and responsibility that will be increased. An adult is expected to take charge of what is happening to himself/herself.

It helps to get ready and be involved in your health care at an early age. It is recommended that an early teen start taking charge of the medical care received. Here is where to start:

- Keep track of your appointments;
- When you arrive at the appointment, check yourself in at the window. Do not rely on a parent or caregiver to do it.
- Keep a list of your medications and update it when changes happen;
- Refill your own prescriptions;
- Know your medical information, like food and drug allergies you may have.

When you switch doctors many practices change. Most individuals must go to a medical practice for adults between the ages of 18 and 21. Often there is a policy on the age at which pediatric doctors no longer see their adult patients. The cut off age might be so fixed that you can make an appointment with your current doctor for one day but not allowed to make one on the next day. The best time to start seeing adult doctors is well before this cutoff age.

Ask your doctor to recommend an adult hematologist (and any other doctors you might need to see) and make your appointment with these new doctors at least a year before your current doctor will have to stop seeing you. That way, if you have questions or if something does not feel quite right, there is time to go back to your pediatric doctor for help making your transition.

TRIVIA

“SIDE” VIEW

BAR	SWIPE	LINE	H E P Y D I W B S Y U L Q X
BET	TABLE	MAN	S Q L M M G M Y O K N I S W
BOARD	TRACKED	PIECE	W T E L D D A S A A L N T U
BURNS	TRIP	SADDLE	I I C T A W H E M I R V C P
CHAIR	WALK	SHOW	P S N E Z W F C G U L D I H
DISH	WALL	SPLITTING	E T T D P F W H B W T E B L
EFFECT	WAYS	STEP	H T K R E W T A L Q C V I K
GLANCE	WHEEL	STREET	D S J C O R I I L E X N K X
KICK	WINDER	STROKE	E I T H I K G R C K E L R R
LIGHT			K K S E U K E N T X R H D N
			C L Y H P G A I K A K F W L
			A C H I V L H U B V B J T W
			R B R W G G N I T T I L P S
			T T I S O N D Z S T R E E T

Annual Holiday Party



On Saturday, December 1, 2018 Santa Claus made his way to the SCANCA, INC. Annual Holiday Party! With plenty of food, drinks, music and games, the holiday party was fun for all. We played Christmas Bingo and musical chairs to the children's delight. Santa had plenty of gifts for all the children who were present, and even some for those who couldn't make it because they were in the hospital. We would like to thank the following organizations for their support of this event: Faces of Our Children, Inc.; The Top Ladies of Distinction, Prince George's Chapter; and the Christopher Gipson Sickle Cell Moya-Moya Foundation. If you couldn't make it, we hope to see you December 2019!

Breakthrough Therapy Designation Granted for Sickle Cell Disease Treatment

Officials with the FDA have granted Breakthrough Therapy designation to Novartis' crizanlizumab (SEG101) for the prevention of vaso-occlusive crises (VOCs) in patients of all genotypes with sickle cell disease (SCD), according to a press release.

Patients with SCD face a high economic burden, with annual costs of more than \$30,000 for adults with the disease, according to Novartis. SCD can lead to VOCs, which are painful complications caused by clusters of cells that block or reduce blood flow.

"Painful sickle cell crises matter because they can disrupt patients' lives, and often require hospital visits and medical attention," Samit Hirawat, MD, head of Novartis Oncology Global Drug Development, said in a statement. "We look forward to working with the FDA over the coming months toward making crizanlizumab, a therapy that has the potential to prevent sickle cell pain crises, available in the US as soon as possible."

Crizanlizumab, a monthly infusion, is a P-selectin inhibitor that reduces VOCs by binding to a molecule called P-selectin on the surface of platelets and endothelium in the blood vessels. It has been shown to inhibit interactions between endothelial cells, platelets, red blood cells, sickled red blood cells, and leukocytes.

Continues on page 5: Breakthrough Therapy

Continues from page 4: Breakthrough Therapy

The designation for crizanlizumab is based on data from the phase 3 SUSTAIN trial, which compared crizanlizumab with a placebo in patients with SCD. Patients in the trial were treated with either crizanlizumab 2.5 mg/kg or 5 mg/kg, or a placebo.

According to the data, crizanlizumab reduced the median annual rate of VOCs leading to health care visits by 45.3% compared with a placebo in patients with or without hydroxyurea therapy. The study also found that crizanlizumab significantly increased the percentage of patients who did not experience any VOCs versus a placebo during treatment.

Adverse events (AEs) that occurred in $\geq 10\%$ of patients in either crizanlizumab treatment group and at a frequency that was at least twice as high as experienced in the placebo group included arthralgia, diarrhea, pruritus, vomiting, and chest pain. Patients who received crizanlizumab (5 mg/kg) experienced a similar incidence of AEs and serious AEs compared with a placebo. Patients receiving crizanlizumab experienced a low 3% incidence of discontinuations due to AEs.

Novartis anticipates filing a New Drug Application for crizanlizumab in the first half of 2019.

2018 “STOMP OUT SICKLE CELL” WALK

SCANCA, INC. Board Members joined Ms. Beverley Francis-Gibson, President of the Sickle Cell Disease Association of America, Inc.; Dr. Sohail Rana and Dr. James Taylor of Howard University at the “STOMP OUT SICKLE CELL” WALK on September 29, 2018. SCANCA, INC. was well represented. Pictures were taken by Mrs. Ocela Briscoe and Mrs. Barbara Harrison was a coordinator for the event. SCANCA, INC. had a table for distribution of Sickle Cell health information.



Ms. Beverley Frances-Gibson with Ms. Beverly Ames & Iola Williams



Dr. Sohail Rana with Ms. Iola Williams



Dr. James Taylor with Ms. Beverly Ames

SICKLE CELL DISEASE IS:

Sickle cell disease (SCD; ORPHA232; OMIM # 603903) is a chronic and invalidating disorder distributed worldwide, with high morbidity and mortality. Given the disease complexity and the multiplicity of pathophysiological targets, development of new therapeutic options is critical, despite the positive effects of hydroxyurea (HU), for many years the only approved drug for SCD. New therapeutic strategies might be divided into (1) pathophysiology-related novel therapies and (2) innovations in curative therapeutic options such as hematopoietic stem cell transplantation and gene therapy. The pathophysiology related novel therapies are: a) Agents which reduce sickling or prevent sickle red cell dehydration; b) Agents targeting SCD vasculopathy and sickle cell-endothelial adhesive events; c) Anti-oxidant agents. This review highlights new therapeutic strategies in SCD and discusses future developments, research implications, and possible innovative clinical trials.

SICKLE CELL AWARENESS BREAKFAST CONFERENCE

SCANCA, INC. compliments Jackmont Hospitality, T.G.I. Friday's Breakfast Club. Twenty-five (25) friends and family of SCANCA, INC.'s Board of Directors members enjoyed a "Chat N Chew" buffet at this Awareness Breakfast Conference on February 16, 2019. The District Heights restaurant breakfast and meeting was hosted by our secretary, Beverly Ames, and enjoyed by all. Also, in attendance was author Jennifer Nsenkyire, an individual who has recovered from a bone marrow transplant curing her of sickle cell disease. She is a living testament who is sharing and encouraging. Thanks again to T.G.I. Friday's Breakfast Club.



VOLUNTEERS NEEDED FOR COMMUNITY HEALTH EDUCATION

Are you able to discuss “Life With Sickle Cell Disease” or any related topic? Do you have a family member or know someone who has sickle cell disease? Would you or that person speak on how the sickle cell individual and the family cope? What can the community do to enhance the life of an individual affected with Sickle Cell Disease? Give us a topic that you or that person can speak on. Contact us on (202) 271-5733 or email at email@scancainc.org. We want to hear from you. It is very important to share experiences. Thank You!!

**SUPPORT THE SICKLE CELL ASSOCIATION
OF THE NATIONAL CAPITAL AREA, INC.
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**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

UPCOMING EVENTS – 2019

SCANCA, INC. SUPPORT GROUP NEEDS LEADERSHIP AND SUPPORT

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

SCANCA, INC. SPRING WORKSHOP

Saturday, May 4 2019 - Luncheon included
8400 Corporate Drive - Landover, Md. 20785
(first floor meeting room – in rear of building)
RESERVATIONS NEEDED – rsvp@scancainc.org

Roland B. Scott Symposium

Tuesday, May 7, 2019
W. Lester Henry Auditorium at Howard University Hospital
Information: 202-865-4578 or
www.ranapediatricfund.org/roland-b-scott

World Sickle Cell Day Symposium

Wednesday, June 19, 2019
In recognition of 10th Anniversary of Sickle Cell Day
Howard University Hospital
Time: 1PM – 5PM
Detail Pending

SOS MOVE-ON-EVENT

September 14, 2019
Howard University Hospital
2041 Georgia Avenue, NW - Washington, DC 20060
9AM – 12Noon
Contact: www.sicklecell.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
Theme: Sickle Cell Community Embracing Change Together
Contact/Information: Office – 410-528-1555 - Web: www.sicklecelldisease.org
Toll Free: 1-800-421-8453, 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

**2019 Scholarship Application
Five Hundred Dollar (\$500.00) Scholarship
DEADLINE: JUNE 30, 2019**

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 2019 application deadline is June 30, 2019. All documents must be enclosed and received by the deadline.

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