



## **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 32

SPRING 2018

### **Education Towards the Management of Sickle Cell**

#### **MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT**

Hello Friends of SCANCA, INC:



**Iola Y. Williams**

The members of SCANCA, INC. wish you many blessings in 2018. We thank you for your love and support over the years.

Please note that SCANCA, INC. **WILL NOT PARTICIPATE IN THE COMBINED FEDERAL CAMPAIGN (CFC) IN 2018.** Therefore, it is more important than ever for you to continue to support us through your donations and gifts. Without them we will not be able to continue our educational programs for families and the community, financial assistance for families, and the scholarship program. Please send your donations to our mailing address or donate through **Paypal** on our website: [www.scancainc.org](http://www.scancainc.org) and click Donation Button.

#### **NEW BOARD MEMBERS**



**DeShon Eason**

DeShon Eason is a native Washingtonian who is affected with Sickle Cell Disease (SC). She obtained a Bachelor of Science Degree from Howard University and a Masters Degree in Physical Therapy from The George Washington University in Washington, D.C. DeShon is currently a practicing physical therapist in Montgomery County, Maryland where she enjoys providing patient care in various settings. She is also a volunteer with the Wendt Center as a board member of Olive Legacy Foundation.



**Toni Eason**

Toni Eason is a native Washingtonian affected with Sickle Cell Disease (SC). She obtained a Bachelor of Science Degree from the University of Maryland and Walden University. Toni also has an award from Rush University. She is a former member of the District of Columbia Board of Nursing and currently sits on the Board of the Olive Legacy Foundation. She practices as a Clinical Nurse Specialist and is passionate about promoting the informed health consumer.

#### **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  
DeShon Eason  
Toni Eason  
Cherrelle Esekie  
Denise Garner  
Barbara Harrison  
Madline Morsha-Taylor**



**Cherrelle Esekie**

Cherrelle Esekie was born in Miami, Florida and raised in Queen Creek, Arizona. Cherrelle and her siblings have Sickle Cell Disease (SC) and attended support meetings as children. This has motivated her to join SCANCA, INC. Since 2011 she personally felt the impact and decided she wanted to make a difference. Cherrelle received her Bachelor of Science Degree from Clark Atlanta University and is currently working on her Masters Degree. She is career driven and a living proof that sickle cell does not stop you from achieving. She hopes to be an advocate for others with sickle cell and is looking forward to the day when this disease is no longer affecting anyone.

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## **SCANCA, INC. AWARDED FIVE SCHOLARSHIPS IN 2017**

Denise I. Garner

Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.) is a community based organization serving persons with sickle cell disease and their families in the National Capital Area (Maryland, Virginia and DC). Part of the mission of SCANCA, INC. is to enhance the education of persons with sickle cell disease by providing a \$500.00 scholarship for students enrolled in institutions of higher learning; e.g., college, technical or graduate school.

If you are a rising freshman, an undergraduate, a graduate student or student pursuing a technical school education we would love to assist you in the pursuit of your education. If you have received a scholarship from us in the past, you are also eligible to reapply as long as you meet the application requirements. An application form is enclosed in this newsletter or you can obtain one from our website at [www.scancainc.org](http://www.scancainc.org) and from the social worker at your medical facility.

**The application deadline is June 30, 2018 with all documents needed. We look forward to hearing from you!!**

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## **HAVE AN ENJOYABLE AND HEALTHY SUMMER! HEALTH TIPS**

**Warm weather has come!!! 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.

## **PEDIATRIC SICKLE CELL ANEMIA TREATMENT GETS GO-AHEAD FROM FDA**

<http://www.raredr.com/news/pediatric.sickle.cell.anemia.hydro.approval>

Mathew Shanley – the U.S. Food and Drug Administration (FDA) granted regular approval to hydroxyurea (Siklos, Addmedica) for the treatment of pediatric patients from 2 years of age and older with sickle cell anemia who have recurrent moderate to severe painful crises.

This is the first FDA approval of the drug intended to be used as therapy in pediatric patients with sickle cell disease. It is designed to reduce the frequency of painful crises and the need for blood transfusions.

Sickle cell anemia is a genetic form of the blood disease in which there are an inadequate amount of healthy red blood cells to carry an appropriate amount of oxygen throughout the patient's body. In sickle cell anemia, red blood cells—normally round—become rigid, sticky, and shaped like a sickle or crescent moon. These sickle cells typically die within 2 weeks, leaving a shortage of red blood cells in the body.

Common symptoms of the condition in pediatric patients include episodic pain, swelling in the hands and feet, delayed growth, impaired vision, and frequent infections. At present, the disease affects about 100,000 U. S. residents.

The approval was based on data from ESCORT (European Sickle Cell Disease Cohort) study (NCT02516570), open-label single-arm trial that enrolled 405 pediatric patients with sickle cell disease from 2-18 years of age. 141 patients from the cohort had not been previously treated with hydroxyurea prior to enrollment, and the drug showed promising safety and efficacy throughout the trial. After 12 months of treatment, the drug exhibited an ability to increase fetal hemoglobin in all patients, and decrease the percentage of patients who experienced at least one vaso-occlusive episode, one episode of acute chest syndrome, one hospitalization due to sickle cell disease or one blood transfusion.

In a study published in the American Journal of Hematology researchers from the St. Jude Children's Hospital presented data from an observational study, HUSTLE (NCT00305175), that confirmed the increase of hemoglobin levels.

“...hospitalizations for the average patient fell to less than one every couple of years rather than four to six annually.” Said lead author Jeremie Estep, M.D., an assistant member of the St. Jude Department of Hematology in a press release. “This frees children from the fevers, pain and other symptoms of this disease and gives them and their families more chances to enjoy childhood and adolescence.

The most common adverse reactions to the drug (incidence.10%) include infections and neutropenia. The recommended initial dose of hydroxyurea is 20 mg/kg once daily.

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### **BIBLE HUMOR**

**We take Scripture seriously, of course, but God also gave us the ability to laugh – and it's healthy to do so!! Enjoy these Bible-based riddles:**

**Q: Who was the fastest runner in the Bible?**

**A: Adam. He was first in the human race.**

**Q: Where is baseball played in the Bible?**

**A: Genesis 1:1 reads “In the beginning.” Then Eve stole first, and Adam stole second. Cain struck out Abel, and soon everything was rained out.**

**Q: Who was the best financier in the Bible?**

**A: Pharaoh's daughter. She went to the Nile bank and pulled out a little prophet.**

**Q: What was Boaz like before he got married?**

**A: Ruthless.**

**Taken from: NewsletterNewsletter Magazine**

# 2017 HOLIDAY PARTY

By Barbara Harrison

We're so happy to report that our 2017 Holiday Party held on December 9, 2017 was a success, despite a few setbacks! The snow came down, but many families were not deterred and came out to fellowship, eat well, and enjoy themselves! Although Santa was not able to attend, many families joined together for a delicious holiday luncheon and fellowship. Thanks to the energy and support of our SCANCA, INC. Board members and associated folks (like Ms. Adrienne – Ms. Garner's daughter turned MC!), the families had a great time, and we created opportunities for all to interact with each other, instead of focusing so much on Santa. Families competed to win prizes, playing "Name that Tune," joined karaoke, dance contest, guessing how much candy was in the jar and how many lights were on the Christmas tree. Music by DJ Frank Evans was at its best, and the luncheon served by Hawkes and Hands Catering was delicious!! Many organizations assisted with the success: Girl Scout Troop #2151 were the Santa elves, Top Ladies of Distinction donated most of the gifts and completely handled set up, Cynthia Gipson and the Christopher Gipson Sickle Cell Moya-Moya Foundation donated gifts and gift cards; Faces of Our Children donated the space, tables and chairs. THANK YOU to all of our partners and to all of YOU for making SCANCA, INC.'s Holiday Party a success!



Top Ladies of Distinction Prince Georges's County Chapter with their Top Teens: Marcus Garvin, Isaiah Harrington, Omar Harrington, Ashanti Mangrum, Carlos Offutt, Frances Ortiz and Joshua White after delivering many gifts.



Cynthia D. Gipson of the Christopher Gipson Sickle Cell Moya Moya Foundation



Karaoke participant



Eric Jones Photographer



D&Hawks Hands Catering



Girl Scout Troop #2151 – Brieanna Womack, Maya Harrison and Miracle Day



Exec. Dir. Ms. Williams, Adrienne Garner, and J. Hawkins, Caterer



Child at play

Holiday Party to be cont'd on page 5



Mr. DJ Frank Evans



Patty Houston and  
Audrey Yu, Registrars



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## EFFECTIVE TREATMENT FOR SICKLE CELL IS HARD TO FIND

Summary by Cherelle Esekie

As an adult Sickle Cell individual, it can be very difficult to be treated properly when encountering a Sickle Cell crisis. Sickle cell disease is an inherited disorder that causes some red blood cells to bend into a crescent shape. The misshapen, inflexible cells clog the blood vessels, preventing blood from circulating oxygen properly, which can cause pain, organ failure and stroke. Many have faced misdiagnosis during a hospital visit which can later lead to their death due to the negligence of the doctors' treatment. In an article Titled: "Sickle Cell Patients Endure Discrimination, Poor Care And Shortened Lives "by Jenny Gold she discusses what many Sickle Cell individuals endure with facing mistreatment. Gold starts with the decrease in life expectancy. It has been found that people with sickle cell disease can expect to die younger than they did more than 20 years ago. One of the most difficult changes for people with Sickle Cell is the transition from children care to adult care. For many adults, finding the right doctor is the most complex search therefore many individuals with Sickle Cell rely on going to the emergency room. The emergency room is only a temporary fix to a serious condition especially dealing with the present opioid crisis throughout America. Treatment can be quite difficult and requires properly trained doctors. However, with recent studies it shows that most physicians who are in the Sickle Cell field are not compensated for their medical service. Good care requires both time and training for not only the doctors but for all Sickle Cell individuals, caregivers, and nurses. Each must be willing to learn more about Sickle Cell and find a treatment that works best for the Sickle Cell individual. I feel that this article by Jenny Gold is a must read for anyone dedicated to the medical field.

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## BE THE MATCH

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

**FOR INFO: 1(800) MARROW-2 BETHEMATCH.ORG**

**Join the Marrow Registry Marrow --- transplant frees the sickle cell sufferer from pain. You only have to be between the ages of 18 & 60, be willing to donate to any patient in need, and meet the health guidelines.**

**DO YOU KNOW THE PARTS OF YOUR BODY?**

- |                                     |   |
|-------------------------------------|---|
| 1. Something to keep tools in _____ | 11. What dogs bury _____                |
| 2. Part of a wagon _____            | 12. Part of a bed _____                 |
| 3. Grown on a cornstalk _____       | 13. Two sailors answering yes _____     |
| 4. A type of macaroni _____         | 14. Branches on a tree _____            |
| 5. A school child _____             | 15. The biggest part of a giraffe _____ |
| 6. Tropical trees _____             | 16. How a wrecked car is moved _____    |
| 7. Part of an apple _____           | 17. Place of worship _____              |
| 8. Used by carpenters _____         | 18. Opposite of the head _____          |
| 9. Edge of a saw _____              | 19. Weapons of war _____                |
| 10. Part of a clock _____           |   |

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**FOOD FOR THOUGHT: WHO WILL ACT FOR YOU IF YOU CAN'T!!**

***“If you have no personal durable power of attorney (POA) and become incapacitated, your relatives will have no choice but to go to court. So please get one!!” A durable power of attorney protects your future self.***

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**DO I NEED A MEDICAL ALERT BRACELET??**

**A:** In a medical emergency, if you are unable to speak or clearly express yourself, a medical alert bracelet can speak for you. A medical alert bracelet gives a brief description of you/your child's unique medical information such as: Sickle cell type and other medical conditions; blood transfusion reactions or special blood needs and medication allergies. This is important so that healthcare providers and emergency responders have access to accurate information. Additionally, this can aid in you/your child receiving faster, safer treatment and avoiding harmful or fatal reactions.

Medical alert bracelets are available in a variety of styles and prices. They can easily be purchased from pharmacies, medical supply and equipment stores or on-line. SCANCA, INC. HAS NO FINANCIAL INTEREST IN THE MEDICAL ALERT DEVICE.

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**\*Answers to Page 6 --DO YOU KNOW THE PARTS OF THE BODY-- 1-chest, 2-tongue, 3-ears, 4-elbow, 5-pupil, 6-palm, 7-skin, 8-nail, 9-teeth, 10-arms, 11-bones, 12-head, 13-eye, 14-limb, 15-neck, 16-toe, 17-temple, 18-foot, 19-hand**

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**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](mailto:email@scancainc.org)

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**SEPTEMBER IS NATIONAL SICKLE CELL MONTH**

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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 – 2018**

**ANNUAL SPRING WORKSHOP**

Saturday, May 5, 2018 -- 12noon – 2pm  
8400 Corporate Drive - Landover, Md. 20785  
first floor meeting room  
Topic to be announced -- Stay tuned to website!!!!  
RESERVATIONS NEEDED – [rsvp@scancainc.org](mailto:rsvp@scancainc.org)  
202-271- 5733 for information

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**World Sickle Cell Day Event**

Howard University Center for Sickle Cell Disease  
Howard University Hospital  
Friday, June 15, 2018 – in the afternoon  
Details to be announced

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**ANNUAL STOMP OUT SICKLE CELL WALK**

September 8, 2018  
For Information: [www.soswalk.org](http://www.soswalk.org)

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**Sickle Cell Disease Association of America, Inc.**

**46<sup>th</sup> Annual National Convention**

October 10-13, 2018  
Hyatt Regency Baltimore Inner Harbor  
Baltimore, Maryland  
1-800-421-8453

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**SCANCA, INC. SUPPORT GROUP NEEDS LEADERSHIP AND SUPPORT**

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

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**SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING**

Available by appointment only.  
Call SCANCA, INC., at 202-271-5733



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