SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC.

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

Volume 29 **FALL 2016**

Education Towards The Management of Sickle Cell

Up to $25 million in Funding for Management of Care Transitions for Emerging Adults with Sickle Cell Disease.

Thanks to the sickle cell community for participating in the "Management of Sickle Cell Disease" workshop hosted by the Patient-Centered Outcomes Research Institute (PCORI) on March 7, 2016. Based on the results of the meeting, we would like to inform you that PCORI will be releasing a new funding announcement titled, "Management of Care Transitions for Emerging Adults with Sickle Cell Disease." The goal of this announcement is to support patient-centered clinical effectiveness research (CER) that focuses on comparing the effectiveness of established transition coordination models for emerging adults (e.g., 16-25 years of age) with sickle cell disease transitioning from pediatric to adult care. Up to $25 million in total costs will be available to support up to three (3) studies in this area. The mission of PCORI is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. The pre-announcement is available on website http://www.pcori.org/funding-opportunities/announcement/management-care-transitions-emerging-adults-sickle-cell-disease

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MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT

Iola Y. Williams

Dear friends: Scientific studies on Sickle Cell Disease have resulted in significant progress over the years. Yet, fear, despair, misdiagnosis, and mistreatment continue. We must encourage our young people to consider a medical career in hematology with focus on Sickle Cell Disease in order to assist the medical professional in caring for the affected. Attending conferences, workshops, symposiums and ALL educational events will improve your knowledge and enable you to better understand what is best for you and other Sickle Cell individuals. Prolong stagnation can be turned around with an increased participation by affected families and their communities. What have you been doing?? We all will benefit from more wide-spread communication to better understand those affected. We are grateful for your support. FOR SOME: **DROP THE FEAR AND MISEDUCATION – GET BUSY LEARNING AND SPREADING THAT WORD. SCANCA, INC. NEEDS EACH OF US. WE NEED SCANCA, INC. PLEASE GET ON BOARD!! THANKS SO MUCH!!**

Iola Y. Williams, RN., Executive Director

SCANCA, INC. 2016 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
Denise Garner
Barbara Harrison
Madline Morsha-Taylor
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CRITICAL INFORMATION TO REMEMBER – DO NOT SUDDENLY GET UP AT NIGHT

For those who get up at night suddenly from sleep to urinate or early morning. Each individual must take note of the 3 x 1/2 minutes. Why is it important? 3 x 1/2 minutes will greatly reduce the number of sudden deaths.

Often when this occurs, a person who looks healthy has died in the night. Often we hear stories of people saying, “yesterday I was chatting with him, why did he suddenly die?”

The reason is that when you wake up at night to go to the bathroom it is often done in a rush. Immediately, we stand, the brain lacks blood flow. Why "3 x 1/2 minutes" is very important? In the middle of the night when you are awakened by the urge to urinate your ECG pattern can change. Because getting up suddenly the brain will be anemic and causes heart failure due to lack of blood. This advises that you practice a "3 1/2 minutes," which are:

1. When waking from sleep, lie idle for the 1st 1/2 minute;
2. Sit in bed for the next 1/2 minute;
3. Lower your legs, sitting on the edge of the bed for the last half-minute.

After 3 x 1/2 minutes, you will not have anemic brain and heart will not fail, reducing the possibility of a fall and sudden death. Share this with family, friends & loved ones. It can occur regardless of age; young or old. Sharing is Caring. “If you already know, regard this as a refresher."

Exploring Adult Care Experiences and Barriers to Transition in Adult Patients with Sickle Cell Disease.

Bemrich-Stolz CJ, Halanych JH, Howard TH, Hilliard LM, Lebensburger JD

Study Abstract

BACKGROUND: Young adults with sickle cell anemia are at high risk for increased hospitalization and death at the time of transition to adult care. This may be related to failure of the transition system to prepare young adults for the adult healthcare system. This qualitative study was designed to identify factors related to transition that may affect the health of adults with sickle cell anemia.

PROCEDURE: Ten patients currently treated in an adult hematology clinic participated in semi-structured qualitative interviews to describe their experience transitioning from pediatric to adult care and differences in adult and pediatric healthcare systems.

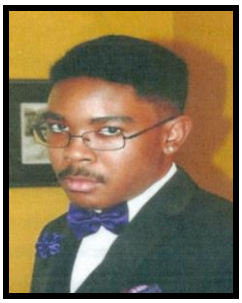
RESULTS: Participants were generally unprepared for the adult healthcare system. Negative issues experienced by participants included physician mistrust, difficulty with employers, keeping insurance, and stress in personal relationships. Positive issues experienced by participants included improved self efficacy with improved self care and autonomy.

CONCLUSIONS: In the absence of a formalized transition program, adults with sickle cell anemia experience significant barriers to adult care. In addition to medical history review and identification of an adult provider, transition programs should incorporate strategies to navigate the adult medical system, insurance and relationships as well as encouraging self efficacy.

BE A BLOOD DONOR - BE THE ANSWER TO THE PROBLEM

SCANCA, INC. 2016-2017 SCHOLARSHIP AWARDEES

Erica Quan



Xavier Ray

Dossou Tchaou

The 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 Washington, DC.) Part of our mission is to enhance the education of persons with sickle cell disease by providing scholarships. This year the scholarship is Five Hundred Dollars ($500.) to students with sickle cell disease enrolled in an institution of higher learning e.g. college, technical school or graduate school.

In 2016, SCANCA, INC. is awarding scholarships to three applicants who are high school seniors. Each one has demonstrated courage and perseverance in overcoming the challenges of sickle cell while pursuing life goals. They have been motivated to achieve a high level of success through high school and now college education while maintaining a “can do” attitude. Their determination does not let the medical condition stand in the way of being the best person they can be.

Erica Quan will be attending Stevenson University in Owings Mills, Maryland. She has a strong desire to be an activist and assist the poor by building schools and hospitals on a global level to give the impoverished a fighting chance in life. Her motto is “Never lose track of who you are because it’s going to be hard to find your true self again.”

Xavier Ray will begin college career at Morgan State University in Baltimore, Maryland where he plans to major in Computer, Mathematical and Natural Science. It is Xavier’s desire to become a Criminal Investigator for the Department of Homeland Security. He was inspired by a program that he participated in with the Department of Homeland Security where he was both a Cadet and a Mentor.

Dossou Tchaou will attend Montgomery College where he plans to major in Electrical Engineering. He plans to obtain an Associate Degree before transferring to the University of Maryland College Park to obtain his Bachelor’s Degree. Dossou became interested in the technology fields related to robotics while in middle school. He has been on a path to increase his knowledge and exposure to that field by attending a high school where he enrolled in the Engineering Program.

SCANCA, INC. applaud the efforts and courage of all of the recipients who not only excelled in academic work but maintained high grade point averages while battling the unpredictable complications of Sickle Cell Disease. We wish each of them much success in their future endeavors.

You can be our scholarship recipient for 2017 by completing the enclosed scholarship application or downloading an application from our website at www.scancainc.org. Our scholarship is not limited to high school students. It is available for any sickle cell individual attending college, graduate, professional or technical school. We want to hear from you!!

Denise I. Garner, Reporter

TRIVIAL

FIVE SIMPLE RULES TO HAPPINESS

1. Free your heart from hatred – Forgive.

2. Free your mind from worries - Most never happens.

3. Live simply and appreciate what you have.

4. Give more.

5. Expect less from people but more from yourself.

Smile and Be Happy!!!

CATCH-UP TIME!!

SCANCA, INC. SPRING WORKSHOP

On April 30, 2016, SCANCA, INC. held its annual spring workshop luncheon in Landover, Maryland. The subject highlighted was: "How to Live Healthy with Sickle Cell Disease." There was a panel comprised of one elementary youth, London Nickols; one senior adult, Madline Morsha-Taylor; and two young adults, Tiffany McCoy and Dietrich Ames. Each of them gave a talk about their life experiences with sickle cell disease and advised the group on how they had stayed healthy and maintained an enjoyable, fulfilling, profitable and prosperous life. There was stimulating interchangeable conversation. Also in attendance was an individual who had a bone marrow transplant in 1991. He looked and seemed to be doing very well. Just his presence and testimony gave us hope. SCANCA, INC. is thankful to the attendees and board members: Barbara Harrison and Cathy McCoy (facilitator) for making this a informational and wonderful workshop.

Beverly Ames, Reporter

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?

***Answers on Page 6**

1. Something to keep tools in _____
2. Part of a wagon_____
3. Grown on a cornstalk_____
4. A type of macaroni_____
5. A school child_____
6. Tropical trees_____
7. Part of an apple_____
8. Used by carpenters_____
9. Edge of a saw_____
10. Weapons of war_____
11. What dogs bury_____
12. Part of a bed_____
13. Two sailors answering yes_____
14. Branches on a tree_____
15. The biggest part of a giraffe_____
16. How a wrecked car is moved_____
17. Place of worship_____
18. Opposite of the head_____
19. Part of a clock_____

NOTE: To enhance our newsletter, we will need your assistance. Please write articles about your life with Sickle Cell and how you or a family member has coped. Include your name, address, email, telephone #, and a picture, if possible, with permission to print in the newsletter.

YOUR EMAIL ADDRESS IS NEEDED TO ECONOMICALLY GET THE NEWSLETTER TO YOU.

PLEASE EMAIL US ON email@scancainc.org or iyw3478@yahoo.com

WHAT YOU CAN AND CANNOT CHANGE!!

There are many things you can change, and there are many things you simply cannot change. Both kinds of things can add value to your life.

With the things you can change, you have the opportunity to improve the circumstances in your own life and in the world around you. In dealing with the things you cannot change, you can grow stronger and develop real wisdom, patience, acceptance, and flexibility.

There is much you can learn from the things you cannot change. You can use that knowledge and experience to positively affect those things you can change.

The things you cannot change give you a base from which to work. The things you can change give you an ever-increasing world of possibilities.

By gently accepting what you cannot change and finding positive ways to deal with it, you lay the groundwork for success. By understanding what you can change and finding positive ways to put that change to work, success and achievement begin to happen.

What a blessing it is to live in a world where there are both things you can change and things you cannot. Each turn of events, in its own way, gives you the opportunity for adding richness to life.

Dr. Lewis Hsu, MD, PhD.
Pediatric Hematologist, Former Director, Sickle Cell Program
Children's National Medical Center, Washington, DC
Now: Pediatric Sickle Cell Director, University of Illinois, Chicago, Illinois

Q: 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 BUSINESS.

EVERYONE SHOULD DRINK PLENTY OF WATER!!.

***Answers to Page 5 --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**

WHAT ARE YOUR ATTENTION REQUIREMENTS?

Tafari Witter is near mid-court, bent forward, tugging on the bottom of his shorts, trying to catch his breath. A substitute is headed to the scorer's table, but Witter looks over to the sidelines and, with a wave of his hand, indicates he's not leaving the game. It might be the only time that Lincoln's starting point guard doesn't have his priorities straight. Witter is a razor-sharp student who is on track to be valedictorian of Lincoln's Class of 2015. He loves Advanced Placement Calculus BC, is part of the Dallas ISD's Future Leaders Program and in the fall will take advance courses leading to a master's degree in business administration. NBA point guard Derrick Rose is among the people who inspire him, but so is a star from a very different arena: theoretical physicist Stephen Hawking. Lincoln coach Cedric Patterson smiles when he hears that. "He's a unique kid," Patterson said. Witter is so unique, and interesting, and engaging, it's hard to squeeze his sickle cell disease into the conversation. And he likes it that way.
http://www.dallasnews.com/sports/high-schools/headlines/20150216-wixon-sickle-cell-disease-cant-hold-back-lincoln-s-tafari-witter-through-sporting-academic-endeavors.ece

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

Living with Sickle Cell Disease http://www.wric.com/story/24263562/positively-richmond-living-with-sickle-cell-disease

RICHMOND (WRIC)—More than 100,000 people across the country suffer from sickle cell disease, a disorder that's more common in African-American families. In Virginia, one in 325 babies is born with the disease. Doctor visits at VCU Medical Center are just a normal part of life for Francis Churchill. He's been living with sickle cell disease for more than 47 years and has one word to describe it: chaos.

The disease keeps Churchill in constant pain. He's had dozens of surgeries, including four on his leg after developing an ulcer."I've had operations on almost every part of my body, especially my joints, because that's where sickle cell attacks—your joints," Churchill said. Sickle cell disease is an inherited blood disorder, and its main symptom is pain. "Pain that causes hospitalization, pain that requires morphine and narcotics, pain that's unremitting—days, weeks at a time," said Dr. Wally Smith, director of the VCU Health Systems Adult Sickle Cell Program.

SEPTEMBER IS NATIONAL SICKLE CELL AWARENESS MONTH

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

Please mail your financial support to: SCANCA, INC., P.O. Box 41479, Washington, DC 20018-0879

E-Mail: EMAIL@SCANCAINC.ORG **COMBINED FEDERAL CAMPAIGN #57433**

COMMUNITY HEALTH CHARITIES Give. Connect. Help.

CFC #57433

UPCOMING EVENTS – 2016

10TH ANNUAL STOMP OUT SICKLE CELL WALK

September 10, 2016

For Information: www.soswalk.org

MARYLAND STATE SICKLE CELL PICNIC

Saturday, September 17, 2016 - 12:00 PM TO 4:00 PM

Druid Hill Park: Parkie Lakeside Pavilion Grove Road
Baltimore Maryland 21217
RSVP by September 13, 2016 - TO: Kim Miller 410-955-6132

44TH ANNUAL CONVENTION OF SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA)

September 27 – October 1, 2016 Hyatt Regency Hotel / Baltimore, Maryland
300 Light Street Baltimore, Maryland 21202
Contact: SCDAA - Office: 1-410-528-1555 - or 1-800-421-8453

SCANCA, INC. ANNUAL HOLIDAY PARTY

Saturday, December 3, 2016 - 11:30 am – 3:00 pm
8400 Corporate Drive, Landover, Maryland 20785
RESERVATIONS NEEDED: rsvp@scancainc.org

SCANCA INC. Executive business meeting
Plymouth Congregational United Church of Christ
North Capital Street and Riggs Road, NE, Washington, DC.
Third Saturday each month 9:30AM -11:30AM – except July and August

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SUPPORT GROUP NEEDS LEADERSHIP AND SUPPORT
Let us know if you would like to assist in this effort.

SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING
By Appointment only - Contact SCANCA, INC. at 202-271-5733

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WASHINGTON, DC. 20018-0879