



**16 YEARS OF SERVICE**

The Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.) has reached its 16<sup>th</sup> Year milestone. On April 23, 1994, SCANCA, INC. was organized under the name of Metropolitan District of Columbia Sickle Cell Disease Association. Mrs. Iola Y. Williams, a Sickle Cell nurse for over 30 years, had a dream for a stable, non-medical community centered organization to promote service and education for individuals with Sickle Cell Disease and their families. We are excited and proud of SCANCA, INC. accomplishments. We invite YOU, the public to come to the workshops offered and attend the group support meetings. SCANCA, INC. is visible at many venues such as Black Family Reunion, Health Fairs, workplace seminars and in schools, teaching staff about the care for individuals with Sickle Cell. With our progression, we now offer a yearly scholarship to Sickle Cell individuals in college or trade school and who are high school graduates going on to obtain further education. SCANCA, INC. scholarship flyer is enclosed for your information and use.

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**TO THE SICKLE CELL COMMUNITY - YOUR HELP IS NEEDED:**

To enhance our newsletter, we need your comments and contributions. We especially appeal to those affected by Sickle Cell. Please write your story and how you are coping/have coped. Your information will educate others and give encouragement. Please include your name, address, email, phone number and a picture if possible. We will also need **your permission** to publicize your comments in our newsletter.

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**TO SCANCA, INC. NEWSLETTER RECIPIENTS:**

**PLEASE SEND US YOUR EMAIL ADDRESS SO THAT WE CAN ECONOMICALLY GET THE NEWSLETTER TO YOU. WE THANK YOU FOR YOUR SUPPORT AND ASSISTANCE.**

**Our email address is: [email@scancainc.org](mailto:email@scancainc.org)**

**MESSAGE FROM THE PRESIDENT  
DIRECTOR**

**MESSAGE FROM THE EXECUTIVE**



Oceola Y. Briscoe

Iola Y. Williams

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## 2010 Census to Begin

Be cautious, so as not to become a victim of fraud or identity theft. U.S. Census workers will count every person in the United States and will gather information about every person living at each address including name, age, gender, race, and other relevant data.

The big question is - how do you tell the difference between a U.S. Census worker and a con artist? BBB offers the following advice: If a U.S. Census worker knocks on your door, he/she will have a badge, a handheld device, a Census Bureau canvas bag, and a confidentiality notice. Ask to see their identification and their badge before giving any information. **Do not** give your Social Security number, credit card or banking information to anyone, even if they claim they need it for the U.S. Census.

**REMEMBER, NO MATTER WHAT THEY ASK, YOU REALLY ONLY NEED TO TELL THEM HOW MANY PEOPLE LIVE AT YOUR ADDRESS. For more advice on avoiding identity theft and fraud, visit [www.bbb.org](http://www.bbb.org)**

### THE POINTING HAND

By: Tykaria Watts

My search has four fingers pointing at me. From my own hands, conceived at my insecurities.

Four fingers pointing at me.

Finding one block and stealing the other was another mental shock.

“You can’t steal someone else’s victory to put together who you would like to be.”

Stepping on toes, chopping smiles as they were beginning to display a sense of happiness and relief,

I wasn’t going to allow it, I was bittersweet.

Four fingers pointing at me.

With sickness in my body there was no excuse because God had been good, never cutting me loose.

But, what was in that other hand was needed so desperately, that breaking down a spirit was an accomplishment strategy.

I have no right to pick and plunder for I’ve allowed the world to throw my spirits under,

In the barn, behind a jammed hatched door, I was not now nor was I ever poor of a kind spirit.

Just webbed in who others thought I was better to be.

Four fingers pointing at me.

My search was for me, straight fingers opened with palms to the sky,

I was ready to receive the definition of me.

No fingers pointing at thee.

I am ready to be. I am ready to be. I am ready to speak..... Life.

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## SICKLE CELL DISEASE - DEFINITIONS TO KNOW

**ANEMIA** - The condition when there is a decreased number of red blood cells.

**BONE MARROW** - the spongy center space inside the bones. Red blood cells are made in the bone marrow.

**GENE** - The basic unit of heredity. Genes determine many different characteristics, including the hemoglobin type. Each individual has two hemoglobin genes, having received one hemoglobin gene from each parent.

**INHERITED CHARACTERISTICS** - Those characteristics that are passed from parent to their biological children by way of the genes.

**HEMOGLOBIN** - The substance in the red blood cells which carries oxygen through the blood circulation. There are many different types of hemoglobin: **SICKLE HEMOGLOBIN (S)** is one type. Some other types of abnormal hemoglobin are "C", "O-ARAB", "BETA-THALASSEMIA", "FETAL", and "ALPHA-THALASSEMIA" the normal hemoglobin is identified as "A" hemoglobin.

**BLOOD COUNT** - The test to measure the amount of hemoglobin in the circulating blood. It indicates if anemia is present.

**RED BLOOD CELLS (Erythrocytes)** - That portion of the blood that carries the hemoglobin. The normal red blood cells live approximately 120 days while the sickle red blood cells live about 30-45 days.

**SICKLE CELLS** - Those red blood cells containing sickle hemoglobin. They are named for their various shapes resulting in a decrease in oxygen content. They often assume a shape resembling the shape of the farm tool called "sickle." This resembles a crescent shaped moon.

**SICKLE CELL ANEMIA** - Results when there is the inheritance of two sickle genes.

**SICKLE CELL DISEASE** - Results when there is the inheritance of one sickle (S) gene and another abnormal hemoglobin gene (S, C, Thalassemia, O-Arab, etc).

**SICKLE CELL TRAIT:** The inheritance of a sickle gene (S) with the normal (S) gene. The normal gene is the predominate gene. This is also called the carrier state; it **is not a disease**.

**SCANCA, INC. IS AGAIN GRATEFUL**



Ardyss International Body Magic, Washington, DC. Also Denae Hilliard represented the National Marrow Donor Program, Columbia, MD. Much gratitude to our beautiful models who exquisitely became live clothes hangers. Glorious Statements is a Christian modeling group promoting plus size women and big/tall men. Participants in picture include SCANCA, INC. Assistant Treasurer Evelyn Ragland, Glorious Statements CEO/President Margaret Carter, SCANCA, INC. Founder/Executive Director Iola Williams, Glorious Statements Vice President/ SCANCA Secretary Beverly Ames and SCANCA, INC. President Oeola Briscoe.

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Prince George's County Chapter of TLOD and its President, Jackie Wilcher. TLOD members pictured are: Lady Roslynn Garvin, Teen Daniela Arcinegas, Teen Erika Liggins, Teen Jasmine Snead, SCANCA, INC. member Fields and Lady Jackie Wilcher.

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### **SICKLE CELL COMMUNITY GETS INFORMATION THROUGH CHURCH NEWSLETTER.**

The Rev. Keith W. Byrd, Sr., pastor of the Zion Baptist Church at 4850 Blagden Avenue, NW, in Washington, DC has designated the year 2010 as the "Year of Partnership." He wants Zion to share and learn from and about others in a loving relationship with Christ. Zion has taken on the community with a "BANG." There are clothing drives, shoe collections, coat give-a-ways, mission visits and many workshops on community relations. Recently they stepped out with a "BLAST" and published two articles for the Sickle Cell Community. These were: **What is Sickle Cell Disease?** and **Health Maintenance in Sickle Cell Disease.** Thanks to the Co-Editors: Uva Sizer and Evelyn Duckenfield. Zion Baptist Church has also considered SCANCA, INC. as one of its outreach missions. We are grateful to Pastor Byrd and the members of Zion Baptist Church.

### **ASK THE EXPERT**

By: Dr. Lewis Hsu, MD, PhD.  
Pediatric Hematologist, Director, Sickle Cell Program  
Children's National Medical Center, Washington, DC

### **WHAT'S THE NEWS IN SICKLE CELL BONE MARROW TRANSPLANTATION (BMT)?**

Answer- Thank you for your question. Bone marrow transplantation offers a cure for sickle cell disease, but is only a good option for a small group of people. That group just got a little bigger when researchers at the National Institutes of Health (NIH) announced early success with a new way to make bone marrow transplantation (BMT) available for adults with sickle cell who were too sick for the standard ways of doing BMT.

### **WHAT ARE THE DETAILS? WHY LOOK AT BMT FOR ADULTS WITH SICKLE CELL DISEASE, NOT CHILDREN?**

Answer- Using the standard BMT approach was fatal for the majority of adults with sickle cell because their organs were damaged by years of living with sickle cell disease. BMT programs excluded adults from this type of BMT, but the increasing life expectancy in sickle cell means there are probably more adults than children with sickle cell in the USA. Many doctors have been looking for new ways for adults with sickle cell disease to have safe and successful BMT. The new approach from NIH features medications that heavily suppress the immune system - like kidney transplantation - instead of using the standard ways of doing BMT. Nine out of ten adults had successful transplants with this new approach and they appear to be cured of sickle cell. The other one adult had Graft Rejection (the transplanted cells did not grow) and still has sickle cell disease but survived.

### **HOW GOOD IS THIS BREAKTHROUGH?**

Answer-This is very good news because it offers hope for adults to have cure by BMT, where standard BMT were often fatal for adults with sickle cell. The 100% survival and 90% cure in these adults with the new immune suppression approach are similar to the success rates in children with the standard BMT approach.

***WATCH FOR MORE INFORMATION ABOUT BONE MARROW TRANSPLANTS - IN FUTURE ISSUES!!!***

SCANCA WORD SEARCH

L Y K A H A L E T G V S O D N  
 Q L I Q I D C V E E E E Z I O  
 R L E M G I I P O D T S C S R  
 H E E C D C O M P L A I N E I  
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 RESEARCH  
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 T I A R T R B R B J G O I C W  
 A M Z U S K T K N I A T I H R

ANEMIA  
 BLOOD  
 COMPLAIN  
 COMPLICATE  
 CRISES  
 INTRAVENOUS  
 SICKLE CELL  
 EDUCATE  
 FAMILY  
 HEALTH  
 HOPE  
 JAUNDICE  
 LEARN  
 PAIN  
 IRON  
 TEACH  
 SUPPORT  
 DISEASE

ACTIVITIES/INFORMATION FOR THE SICKLE CELL COMMUNITY

**Cholesterol-lowering drug shows promise against serious infections in sickle cell disease**

*St. Jude Children's Research Hospital scientists lead effort that identifies a novel way statins protect cells from a host of bacterial toxins*

**MEMPHIS, Tenn. – January 19, 2010**) New research suggests a family of widely used cholesterol-lowering drugs might help protect individuals from serious illness following bacterial infection, including the pneumococcal infections that pose a deadly threat to those with sickle cell disease.

Research led by St. Jude Research Hospital investigators reported called statins employ methods to dampen inflammation and block pneumococcus and

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Children's that drugs several

and other bacteria from infecting cells and spreading throughout the body. Elaine Tuomanen, M.D., St. Jude Infectious Diseases chair, said those methods include a newly identified mechanism that statins use to protect healthy cells by blocking the toxicity of an entire class of bacteria. Along with pneumococcus, that class includes diphtheria, tetanus, listeria and group A streptococcus, which is also known as the flesh-eating bacterium. Tuomanen is co-senior author of the study with Carlos Orihuela, Ph.D., University of Texas Health Science Center at San Antonio (UTHSCSA). The work is published in the January 19 advanced, online edition of *The Journal of Clinical Investigation*.

The results provide the foundation for a possible future study to determine if statins, already widely used to lower cholesterol in adults, might protect children with sickle cell disease (SCD) from serious pneumococcal infection. SCD is an inherited blood disorder. The findings also suggest statins might protect others at high risk for pneumonia due to chronic inflammation of the lungs or blood vessels. In this study, scientists reported that statins prolonged the lives of mice with sickle cell disease following infection with the pneumococcal bacteria. Researchers also reported that a day after being infected, the treated mice had fewer bacteria in their lungs and blood, suggesting statins slowed the spread of the infection. Full Text of the journal article [http://www.jci.org/articles/view/39843?search\[article\\_text\]=&search\[authors\\_text\]=rosch](http://www.jci.org/articles/view/39843?search[article_text]=&search[authors_text]=rosch)

**Sickle Cell Mom** - at <http://sicklecellmom.wordpress.com/> Sickle Cell Mom is a mother parenting someone with Sickle Cell or a mother who has Sickle Cell herself. I've long needed a place to journal and express my thoughts and experiences as a Sickle Cell Mom. I plan to keep it real, informative and definitely inspirational.

**May 14, 2010 New York, NY** An All Day Symposium : Sickle Cell Disease at 100 The latest

SCANCA, INC. 2010  
 BOARD OF DIRECTORS

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Advances in Treatment May 14, 2010 Sponsored by the Comprehensive Sickle Cell/Thalassemia Program At New York Methodist Hospital Brooklyn, New York 718-857-5643.

**July 15 - 18 Kiawah Island Resort near Charleston, South Carolina - 10th Annual Using Transcranial Doppler, MRI/MRA and Transfusion to Prevent Stroke in Sickle Cell Disease.** This activity has been approved for AMA PRA credit. For more information, contact:Office of Continuing Medical EducationMedical University of South Carolina, Charleston, SC 29425. Phone: 843-876-1925 • Email: [maxwells@musc.edu](mailto:maxwells@musc.edu)

**July 20-23, 2010 Accra, Ghana** within the *First Global Congress on Sickle Cell Disease*, July 20-23, 2010, co-sponsored by the Sickle Cell Center at Children's Hospital of Philadelphia and The Sickle Cell Foundation of Ghana. For information email [sicklecellsymposium@email.chop.edu](mailto:sicklecellsymposium@email.chop.edu)



### TRIVIAL - KNOW THE SYMPTOMS

I know you are not old enough for this yet, but your day is coming (smile). Thank goodness there's a name for this disorder. Somehow I feel better, even though I have it! Recently, I was diagnosed with A.A.A.D.D. - Age Activated Attention Deficit Disorder. This is how it manifests:

I decide to water my garden. As I turn on the hose in the driveway, I look over at my car and decide it needs washing. As I start toward the garage, I notice mail on the porch table that I brought up from the mail box earlier. I decide to go through the mail before I wash the car. I lay my car keys on the table, put the junk mail in the garbage can, under the table, and notice that the can is full. So, I decide to put the bills back on the table and take out the garbage first.

But then I think, since I'm going to be near the mailbox when I take out the garbage anyway, I may as well pay the bills first. I take my check book off the table, and see that there is only one check left. My extra checks are in my desk in the study, so I go inside the house to my desk where I find the can of Coke I'd been drinking. I'm going to look for my checks, but first I need to push the Coke aside so that I don't accidentally knock it over. The Coke is getting warm, and I decide to put it in the refrigerator to keep it cold.

As I head toward the kitchen with the Coke, a vase of flowers on the counter catches my eye--they need water. I put the Coke on the counter and discover my reading glasses that I've been searching for all morning. I decide I better put them back on my desk, but first I'm going to water the flowers. I set the glasses back down on the counter, fill a container with water and suddenly spot the TV remote. Someone left it on the kitchen table.

I realize that tonight when we go to watch TV I'll be looking for the remote, but I won't remember that it's on the kitchen table, so I decide to put it back in the den where it belongs, but first I'll water the flowers. I pour some water in the flowers, but quite a bit of it spills on the floor. So, I set the remote back on the table, get some towels and wipe up the spill. Then, I head down the hall trying to remember what I was planning to do.

At the end of the day the car isn't washed the bills aren't paid there is a warm can of Coke sitting on the counter the flowers don't have enough water, there is still only one check in my check book, I can't find the remote, I can't find my glasses, and I don't remember what I did with the car keys. Then, when I try to figure out why nothing got done today, I'm really baffled because I know I was busy all day, and I'm really tired. I realize this is a serious problem, and I'll try to get some help for it, but first I'll check my e-mail.

Do me a favor. Let someone else know about this, because I don't remember who I've sent it to. Don't laugh -- if this isn't you yet, your day is coming!!

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\_\_\_\_One Year Membership Dues \$25.00

\_\_\_\_Organizations/Corporations \$100.00

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\_\_\_\_\_ 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](mailto:EMAIL@SCANCAINC.ORG) **COMBINED FEDERAL CAMPAIGN #57433**

Sickle Cell Association of the National Capital Area, Inc. is a  
NONPROFIT, TAX EXEMPT ORGANIZATION

### **UPCOMING EVENTS - 2010**

#### **SCANCA, INC. SPRING WORKSHOP**

**Saturday May 1, 2010 -- 9:00 AM – 11:00 AM** -- Continental Breakfast 8:00 AM – 8:45 AM  
Plymouth Congregational Church (Chapel) --- 5301 North Capitol Street, Washington, DC  
(North Capitol and Riggs Road) 3 blocks from Ft. Totten Metro Station (Red Line)  
A CHURCH SPONSORED HEALTH FAIR WILL IMMEDIATELY FOLLOW --- **FREE TO ALL**

#### **SCANCA INC. Executive business meeting**

Plymouth Congregational Church  
Third Saturday each month 9:30 AM - 11:30 AM - except July and August

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

**By Appointment Only**

Contact: SCANCA, INC. office - 202-271-5733

#### **SUPPORT MEETINGS**

#### **FACAS– (Families Advocating for Children and Adults with Sickle Cell Disease**

Fourth Saturday of EVERY month: 10:00: AM – 12 Noon

UCFW 400 Building- Metro 400 -- 4301 Garden City Drive, Hyattsville, MD 20785

Metro transportation, New Carrollton Exit (right)

For information, verification of date or directions contact SCANCA, INC. – Barbara Harrison at 202-806-6329,

email: [bwharrison@howard.edu](mailto:bwharrison@howard.edu) or Esther Agbaja at 757-651-2162, email: [coa319@gmail.com](mailto:coa319@gmail.com)

#### **2nd World Sickle Cell Day, June 19, 2010 - Multi city world wide**

Sickle Cell Avocacy Day on Capitol Hill -- March 25, 2010

For information: [Shirleyrenee3@gmail.com](mailto:Shirleyrenee3@gmail.com) or Ann Burke at 1-800-421-8453

#### **STOMP OUT SICKLE CELL WALK (SOS) -- September 18, 2010**

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(SCANCA, INC.)

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*Education Towards The Management of Sickle Cell*

**2010 Scholarship Application**  
**Five Hundred Dollar (\$500.00) Scholarship**  
**DEADLINE: JULY 30, 2010**

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 \_\_\_\_\_

Attach the following:

1. Letter from doctor/nurse/ social worker verifying Sickle Cell Disease;
2. Graduating High School Senior or College Student letter of acceptance from prospective 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 describing your goals and aspirations (200 word limit). Include a recent photo.

**Applicant must be a resident of the Washington, D.C. Metropolitan Area**

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