

# SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC.



## Education Towards The Management of Sickle Cell

P.O. Box 41479 - Washington, D. C. 20018-0879  
CFC #57433 -- 202-271-5733 -- FAX: 202-239-4789  
[www:scancainc.org](http://www.scancainc.org) - [email@scancainc.org](mailto:email@scancainc.org)

## SEPTEMBER IS NATIONAL SICKLE CELL MONTH

Volume 19

FALL 2009

## Combined Federal Campaign (CFC) OPEN SEASON IS UPON US

**QUICK, BEAT THE CROWD -- GIVE NOW!! -- SCANCA, INC. #57433**

### SCANCA, INC. WORKSHOP

### "LIVING A FULL AND SUCCESS LIFE WITH SICKLE CELL DISEASE"

On Saturday, May 2, 2009, SCANCA, INC hosted a workshop entitled "LIVING A FULL AND SUCCESS LIFE WITH SICKLE CELL DISEASE." This workshop allowed individuals with sickle cell, their families and the community to get a glimpse of the productive and full life that those affected by sickle cell can enjoy, if he/she takes care of himself/herself. We introduce to you our special guests:

#### **DR. EDWARD DONNELL IVY, MPH.**

Dr. Edward Donnell Ivy was raised in a family with five children (3 brothers and 1 sister). When he was two years old, his family was told that he had Sickle Cell Disease. What a shock! He was raised by his grandmother, who used the old school remedies for everything. Grandma pushed him to do chores, depend on self and never to stop until the task is complete.



At an early age Dr. Ivy had a dream to become an Air Force pilot. That dream never left his mind. Throughout the years of multiple crises he would never miss school, of course, unless Grandma really believed this was necessary. As a youth, he developed acute chest syndrome and found himself in ICU with a nurse at his bedside at all times.

When Dr. Ivy and his grandmother moved to South Carolina, he met a doctor who specialized in Sickle Cell Disease. This doctor took special interest in him, not as a patient but as a human being. It was not about the disease but about the whole being. Dr. Ivy then took medication with many side effects but did not give up. This doctor attended him through episode after episode until he was capable of taking complete care of himself. With that care Dr. Ivy prepared for college by working in the lab with this doctor. The encouragement was never ending and Dr. Ivy enrolled into medical school. He then developed necrosis in both hips causing him to eventually have a double hip replacement.

Dr. Ivy completed medical school and is now a medical doctor specializing in research and Pediatrics. He realized that because of Sickle Cell Disease he would not be able to be that pilot. He had to jump many barriers and wishes that all young people would realize the many advantages that are out there for them. Children today are not preparing themselves for the future. They and their parents must search for these advantages and use organizations such as SCANCA, INC. to get the needed information. Dr. Ivy went into Public Health and also received his Masters Degree. In residency he preached to the families that "every sickle cell individual should go to college." The individual with sickle cell is able to study in any field he/she aspires to. No, it's not easy but you can excel if you keep at the task. We also are more aware that the life expectancy of the individual with sickle cell has long been improved.

Get involved! Dr. Ivy wants you to succeed and tell others of your success. **THANK YOU, DR. IVY!!**

Continue on page 3

#### SCANCA, INC. 2009 BOARD OF DIRECTORS

##### Officers:

*Iola Y. Williams - Executive Director  
Oceola Y. Briscoe - President  
Barbara Harrison - Vice President  
Beverly Ames - Secretary  
Lorenzo Nichols, Jr. - Treasurer  
Evelyn Ragland - Assistant Treasurer*

##### At-Large:

*Ella Cook  
Denise Garner  
Dr. Lewis Hsu  
Nicole D. James  
Deattra Perkins  
Robert Richards, Esq.  
Rev. A. Rebecca West*

## MESSAGE FROM THE PRESIDENT



Greetings Friends and Members:

The year is really moving on.... Here it's September 2009. I am very thankful for your support and wish you a blessed end to 2009. Remember that September is National Sickle Cell Month. Do something special for SCANCA, INC. now.

Our work is non-ending. Because of your support we are able to assist many families and individuals with Sickle Cell in some of the trials of life. It's FALL and time for us to spread our wings and end the year by giving a blessing to someone else whereby we will receive a blessing. Come on!!! Make us work with you and for you during this blessed Thanksgiving and Christmas season.. "If it is to be, it is up to you and me." I am going to be here. What about you???? Please join me!

Remember to include us in your Combined Federal Campaign Fund: **CFC # 57433**. Without you it cannot and will not be done. Be blessed.

Oceola Y. Briscoe

## MESSAGE FROM THE EXECUTIVE DIRECTOR



Greetings to all,

A poem has lingered with me - "If times are hard and you feel blue, think of others troubles too". I've spoken with many of you and find that many of the same fears and concerns have lingered over the years. This is true with the newly diagnosed families as well as the young adults and the seasoned adults. I often wonder where are you who are experienced and have weathered the storm? We need the experienced individuals to assist those with concerns and fears. Remember, the help you needed. Let's help others more! We encourage those who have questions or just need a listening ear to call. You will receive a response.

Join the support group (see the "Events" item). Keep the faith! Remember, "Those who travel fortune roads may often bear the biggest load". Get involved. SCANCA, INC. is here to assist in your effort.

God bless you all. Have a wonderful Holiday Season and enjoy a beautiful and full life with gratitude and a smile.

Iola Y. Williams

**Note: To enhance our newsletter we need input and contributions from you, the reader. We especially appeal to those affected by sickle cell. Please write articles about your life with the disease and how you have coped. You can write about anything you think can help to educate or share some insight to others. Please include your name address, e-mail address, phone number, and a picture, if possible.**

**YOUR EMAIL ADDRESS IS NEEDED TO ECONOMICALLY GET THE NEWSLETTER TO YOU.  
PLEASE EMAIL US ON: [email@scancainc.org](mailto:email@scancainc.org) or mail input to [iyw3478@yahoo.com](mailto:iyw3478@yahoo.com)**

### NOTE OF APPRECIATION

The SCANCA, INC. Board of Directors wish to thank our member, Lorenzo Nichols, who with his wife, Veronica (passed on November 20, 2006), were the editors of this newsletter from its inception in 1998. Their hard work is much appreciated. That assignment has now been passed to our President, Oceola Briscoe. Mr. Nichols continues as our Treasurer. Best wishes to him and his son, Zakee.

Continued from page 1

**MS. LESLIE AUSTIN**



Ms. Leslie Austin one of two daughters whose parents sheltered them from everything. Of course, when they were told that their first child had Sickle Cell Disease, they were devastated. After years of seeking care for Leslie, the family finally came to Children's National Medical Center in Washington, DC., where they met Nurse Iola Williams. Mrs. Austin had much anxiety since Nurse Williams was not a doctor. She did not want to hear about Sickle Cell Disease but wanted someone, anyone, to take this disease away from her child. Ms. Austin had received many transfusions due to low blood counts and no one seemed to know what caused this.. With superb medical follow-up, examinations and education Mrs. Williams identified the problem as Splenic Sequestration. Of course this cemented a strong positive relationship between this family and the nurse.

Mrs. Austin was determined that her daughter was going to do all those things that she had been planned for her life-- good grades and a college education which could lead to a good career. Leslie always wanted to be a teacher. She had to cross many hurdles to reach her goal. Like many young people, she did not always follow the advice of the medical staff. During her senior year in high school she had the opportunity to visit Mexico on a class trip. Though they were warned against drinking the water, Leslie used the ice cubes. This resulted in a massive Salmonella infection of the bones and blood.. What is ice but frozen water? That was a bitter lesson and she loss much time from school. However, her mother made sure that she had a tutor. Ms. Austin was such a great student that she was able to graduate from high school on time with her class. She has since had a hip replacement.

Leslie feels fortunate to be able to tell her story and feels that this workshop has allowed individuals with sickle cell, their families and the community to get a glimpse of the productive life that can be had, even with road blocks. She graduated from Catholic University and has been a teacher in the District of Columbia for many years.

At this point in her life, Ms. Austin lives a good life. She wants you to know that a successful life is up to you. Each individual, and especially the individual with sickle cell, must follow all advice and instructions given so that some of the downfalls will not be experienced. You too can live a successful good life. Get educated! IT IS UP TO YOU! THANK YOU, MS. AUSTIN!!

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**OUR 2008 SERVICE REPORT TO YOU!!**

**SCANCA, INC. is proud to inform you that over \$17,000.00 in services were expended for the year 2008. Much more was donated in educational and health awareness services. We do thank all for your contributions. A special thanks to the CFC #57433!**

**We provide services through workshops, health fairs, school visits, crisis support, social interactive activities, and scholarships. Our education and support services are always FREE. Encourage your school, church or community organization to have SCANCA, INC. talk with their group on the many preventive and health care needs related to the individual with Sickle Cell Disease.**

**We thank you for supporting this service organization.**

**THE EXECUTIVE BOARD OF SCANCA, INC.**

# SCANCA Word Search

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

ADULTS  
 ANEMIA  
 CELL  
 CHILDREN  
 CRISIS  
 CURE  
 DONATE  
 EDUCATE  
 EXERCISE  
 FLUIDS

HEMATOLOGY  
 HEREDITARY  
 PAINFUL  
 SCANCA  
 SICKLE  
 SPLEEN  
 SUPPORT  
 TRAIT  
 WALK  
 WORKSHOP

## ASK THE EXPERT

By: *Dr. Lewis Hsu, MD, PhD*

*Pediatric Hematologist, Director, Sickle Cell Program  
Children's National Medical Center, Washington, DC*

### WHAT VITAMIN SUPPLEMENTS SHOULD I GIVE MY CHILD WITH SICKLE CELL DISEASE??

**Answer** - Thank you for your question. There has been some research on vitamin supplements in sickle cell disease, mostly small studies. I am not aware of any single vitamin supplement that showed huge benefits, and some studies are now looking at combinations of vitamins & nutritional supplements. Folate 1mg per day is prescribed by many hematologists for people with hemolytic anemia, although the research for the need for folate were done before the time of national folate fortification of foods (To prevent birth defects, the U.S. has since 1998 required enrichment of cereal-grain products with folate.) Until there are more research results, I would suggest a common-sense approach to vitamin supplements & intake:

- (1) a regular daily multivitamin without iron, but with trace mineral;
- (2) avoid mega-dose vitamins that exceed the recommended daily allowance. These may not hurt, but are probably a waste of money;
- (3) folate 1mg per day if your hematologist prescribes it;
- (4) balanced diet with lots of fruit, vegetables, lower in animal fats & higher in omega-3 fats found in cold water fish;
- (5) drink water rather than sodapop.

**REMEMBER YOUR SPECIAL DAYS:** Christmas, Columbus Day, Halloween, Hanukkah, Kwanzaa, Thanksgiving, Veterans, Yom Kippur, Rosh Hashanah, Labor Day, Fall and Winter Seasons

## SICKLE CELL DISEASE WORLD DAY

### The United Nations declared June 19, 2009 as the "First Sickle Cell Disease World Day"

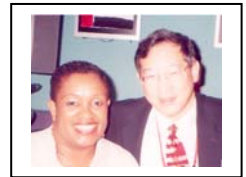
On December 22, 2008, the United Nations General Assembly adopted Resolution A/63/1.63 recognizes sickle cell disease as a public health problem. Among the objectives of this resolution, initiated by Sickle Cell Disease International Organization (SCDIO), proposed by the Delegation of the Republic of Congo Brazzaville and co-sponsored by 24 Member States; is to devote a day to awareness at national and international levels. This celebration on the 19<sup>th</sup> of June each year was formally celebrated by SCDIO since 2001.

#### LOCAL CELEBRATION OF FIRST SICKLE CELL DISEASE WORLD DAY

On Friday, June 19, 2009, the first **SICKLE CELL DISEASE WORLD DAY** was celebrated at the Children's National Medical Center (CNMC) in Washington DC. It was coordinated with the Child Health Advocacy Institute. SCANCA, INC. was represented by our President, Mrs. Oceola Briscoe and Executive Director, Mrs. Iola Williams. It was a celebration of the United Nations Proclamation A/63/1.63.

Our executive director was well received by the Sickle Cell Community who already knew her. Dr. Joseph Wright, an advocacy spokesperson for CNMC, and Ms. Jacqueline Bowen, a staff member at CNMC, welcomed those present. This was a luncheon reception program. The presenters included Dr. Joseph Wright, who had been a working partner with Ms. Iola Williams at CNMC; Ambassador Abdoulaye Diop, Embassy of Mali; Ambassador Hawa Ndilowe, Embassy of Malawi; Muftau Shinaba, a ten year old, who shared his Sickle Cell experience; and Mr. Bobby Engram, of the Bobby Engram Foundation., a parent of a Sickle Cell individual; **Dr. Lewis Hsu**, a SCANCA, INC. member and the CNMC, Sickle Cell Division Director. **Mrs. Audrey Williams**, a mother who also spoke, graciously agreed to have her presentation printed in the SCANCA, INC. newsletter. It follows:

"Good Afternoon, my name is Audrey Williams, the mom to 10 year old Paul Williams. Paul has been a patient at Children's Hospital since he was diagnosed at birth with Sickle Cell Disease. I have worked closely with his medical team and with his pediatrician to make sure he gets the best care possible.



*Mrs. A. Williams-Dr. Hsu*

From the beginning I learned everything I could about the disease and was familiar with it as my brother and aunt have the disease. Most importantly, I learned the value of patience - patience with Paul's recovery from his pain crisis. I learned to be a "nurse mom" rubbing those painful areas and helping him to stay hydrated or remembering when to give him medications. I also learned what clues and symptoms to watch for that could bring on a crisis.

I have to teach Paul about his limits- what he can and cannot do and why he cannot play football or cannot go swimming in cold water. For Paul "no" means "I'll try anyway." Sickle Cell disease does not define him. He works around it. If he has five minutes of feeling good - he will live life to the fullest- even if it means being in pain afterwards. I am grateful for the new therapies and treatments that help him to live an active life. He plays soccer, swims and is a bright, rough and tumble ten year-old boy. The toughest thing for Paul is trying to be a normal child and not letting others know he has the disease. He believes that if other children know about his pain crisis, then they will think he is weak. We continue to work on that.

I can not say enough about the wonderful care Paul gets at Children's National Medical Center/Hospital. We live about thirty minutes from there and if we need to get to the emergency room, we would rather drive past several other hospitals because the medical team at Children's understands how to treat Sickle Cell and that makes a big difference. Thank you to the hematology staff of doctors and nurses at Children's.

Caring for Paul is by no means an easy task. My husband and I work around monthly hospital clinic visits. If Paul misses school we work closely with his teachers to get him make-up work. Thankfully Paul has kept up with his classes and is doing very well. Hospital stays have become routine. I once got dressed for a job interview right in his hospital room. I did get the job.

I would urge policy makers to continue to fund much needed research for Sickle Cell Disease. We also need to raise awareness among parents of African American children that there are treatments available for this disease. To the philanthropists out there - please help set up more Sickle Cell clinics in more hospitals in urban areas.

I hope that I will live to see my child have a life free of pain and that he will realize his dream of becoming an international soccer player. Please remember that we must fund more research, create awareness and bring more care closer to those who need it. I ask President Obama to please remember to set aside funding for Sickle Cell Disease as he works to overhaul health care. Thank You."

## TRIVIAL - - DID YOU KNOW????

### The True Philosophy Of Love....

If you truly love something, set it free.  
If it comes back, it will always be yours.  
If it doesn't, it was never yours to begin with.

### BUT...

If it just sits in your living room, watches your TV, messes up your stuff, eats your food, uses your telephone, takes your money, and doesn't appear to realize that you actually set it free in the first place....

Your either married it or gave birth to it!

Author Unknown

## SENIOR DRESS CODE

Many of us over 50, WAY over 50, or on the way to 50 (not that you all are) are quite confused about how we should present ourselves. We're unsure about the kind of image we are projecting and whether or not we are correct as we try to conform to current fashion. In spite of what you may have seen on the streets, the following combinations **DO NOT go together and should be avoided**:

1. A nose ring and bifocals
  2. Spiked hair and bald spots
  3. A pierced tongue and dentures
  4. Miniskirts and support hose
  5. Ankle bracelets and corn pads
  6. Speedo's and cellulite
  7. A belly button ring and a gall bladder surgery scar
  8. Unbuttoned disco shirts and a heart monitor
  9. Midriff shirts and a midriff bulge
  10. Pierced nipples that hang below the waist
  11. Bikinis and liver spots.
  12. Short shorts and varicose veins.
  13. Inline skates and a walker..
- And the ultimate 'Bad Taste' in fashion for the older folks...  
14. Thongs and Depends.

Please keep these basic guidelines foremost in your mind when you shop.

## ON-LINE BONE MARROW DRIVE

From the National Marrow Donor Registry – The process for individuals to join the online WSCD Marrow Drive: Go to [www.Bethematch.org](http://www.Bethematch.org). You will be instructed what to do. Equipment will be mailed to you with instruction to return swab in pre-addressed envelope.

Those who wish to organize free drives (it is recommended that at least two people from each organization registers) are requested to participate in a training program. Please contact **Shelley D. Baker**, Account Executive for Be The Match Registry, 1231 E. Dyer Road, Suite 236, Santa Ana , Ca. 92705, office (714)800-1610, cell (714)296-8479, fax (714)662-4465, email:[sbaker@nmdp.org](mailto:sbaker@nmdp.org), who will provide the training throughout the US and world.

## HEALTH TIPS

### CONTROL THESE RISK FACTORS:

Preventive measures are important both for those who have had heart attacks and for those who haven't.

1. **HIGH BLOOD PRESSURE** (hypertension)-- too much force continually pressing against artery walls by flowing blood. Uncontrolled high blood pressure strains the heart, increasing the risk of heart attack and stroke. It can be controlled by taking prescribed drugs, maintaining proper weight, eating right, reducing salt intake and getting regular exercise and relaxation.

HAVE YOUR BLOOD PRESSURE CHECKED REGULARLY.....

2. **STRESS** --emotional pressure that makes you feel tense. Although some stress is unavoidable, too much may contribute to heart attacks in some people. Try to identify problem situations in your life and start to change them. Plan your work. Take time for breaks. Set realistic goals, and don't try to "race the clock." Set aside time for relaxation. Try new activities and hobbies.



**SOOO. PROTECT YOUR HEART AND YOUR LIFE !!**



**SOS (Stomp Out Sickle Cell) Walk**  
 --- September 19, 2009 8 AM – 10 AM  
 Route: Start and end: Howard University Hospital  
 2041 Georgia Avenue, NW  
 Washington, DC  
 Mid Point: Children’s National Medical Center  
 111 Michigan Ave., NW  
 Registration online: [www.soswalk.org](http://www.soswalk.org)  
 Or call: 202-865-4443 or 1-866-322-3711

**NOTE: SCANCA INC. Executive business meeting**  
 Plymouth Congregational Church  
 Third Saturday each month 9:30 AM - 11:30 AM  
 except July and August

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**SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING**  
**By appointment Only**

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

\_\_\_\_\_ 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](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 2009 - 2010

### SUPPORT MEETINGS

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

Fourth Saturday on EVEN months: 10:00: AM – 12 Noon --- Next meetings August 22 & October 24, 2009  
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 Ella Cook at 202-246-6435, email: [ecook0811@yahoo.com](mailto:ecook0811@yahoo.com)

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#### **HOLIDAY PARTY - DECEMBER 5, 2009**

**Please call our office at 202-271-5733 to register,**

give your name, the number of persons coming and email or telephone number

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#### **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 IMMEDIATELY FOLLOWING --- **FREE TO ALL**

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