

SICKLE CELL ASSOCIATION NATIONAL CAPITAL AREA, INC.



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CFC #57433 -- 202-271-5733 -- FAX: 202-239-4789
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Education Toward The Management of Sickle Cell
501(c)(3) NONPROFIT, TAX EXEMPT ORGANIZATION

SEPTEMBER IS SICKLE CELL AWARENESS MONTH

Volume 21

FALL 2010

100 YEARS OF SICKLE CELL DOCUMENTATION

Historical Significance

By Dr. William P. Winter, Ph.D., Deputy Director of the Howard University
Center for Sickle Cell Disease

In the annals of medical history, 1910 is regarded as the date of the discovery of sickle cell disease, making 2010 the 100th anniversary of that discovery, but just what does it mean to say the disease was “discovered”? The disorder we call “Sickle Cell Disease,” often abbreviated as SCD, had been present in Africa for at least five thousand years and had been known by many names in many tribal languages. What we call its “discovery” in 1910 occurred, not in Africa, but in the United States. A young man named Walter Clement Noel from the island of Grenada, a dental student studying in Chicago, went to Dr. James B. Herrick, cardiologist, with complaints of pain episodes, and symptoms of anemia. A hematologist, Dr. Irons examined Noel’s blood under the microscope and saw red blood cells he described as “having the shape of a sickle”. When Dr. Herrick saw this in the chart, he became interested because he saw that this might be a new, unknown, disease. He subsequently published a paper in one of the medical journals in which he used the term “sickle shaped cells.”

As more cases began to surface, the mystery of just what this disease was only deepened. It was clear that for whatever reason it seemed to occur only or primarily in persons of African origin. In 1927 Drs. Hahn and Gillespie discovered that red blood cells from persons with the disease could be made to sickle by removing oxygen. This was exciting because red cells are the oxygen transporters of the body. The trouble was, that there were people –often relatives of the patient – whose red cells had this trait of sickling when deprived of oxygen but who had no disease. This condition became known as “sickle trait”.

In the late 1940’s and early 1950’s the nature of the disease began to become clearer. In 1949, two articles appeared independently showing conclusively that SCD was inherited and that people with sickle trait were heterozygous (carriers or AS) for the gene whereas people with the disease were homozygous – i.e., had a double sickle gene (SS). One was published by a military doctor, Col. E.A. Beet, in what was then known as Portuguese East Africa (now Mozambique). His article was in an African medical journal. The other was by Dr. James V. Neel, Chairman and founder of the Department of Human Genetics at the University of Michigan.

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Two years later, in 1951, the famous Nobel Prize-winning chemist, Dr. Linus Pauling and his colleague Dr. Harvey Itano, discovered that the red, oxygen-carrying protein called "hemoglobin" had a different chemical structure in persons with SCD. This led Dr. Pauling to coin the term "molecular disease" for disorders that resulted from proteins with abnormal chemical structures. Today, thousands of such diseases are known but in 1951, SCD was the first. The details of the abnormality were worked out by Dr. Vernon Ingram in 1956. In the 1970's, more details of how this abnormal structure affects the red blood cells were revealed and better tests for the detection of the disease were developed. In the years following, better ways of treating sickle cell individuals and potential treatments appeared. Thus, the life span and the quality of life of individuals with sickle cell are greatly improved.

Today, 100 years later, physicians and scientists continue to move forward with a new understanding of the disease and new ways to treat it. The goal of a total cure has not been reached but great progress has been made. Perhaps within the lifetime of some of us, that goal will be reached. It is important that you use your knowledge of this disease as an opportunity to raise awareness of sickle cell disease in our community. We need your help!

MESSAGE FROM THE PRESIDENT



Oceola Y. Briscoe

To our SCANCA, INC Supporters and Friends:

We are at the end of 2010... What accomplishments have you made to SCANCA, INC.? We appreciate your past support but need more of you to support our activities. Let us know your interests, email addresses and what you would like to see in your newsletter. Our continual interest is the Sickle Cell Community... That is the reason we are here. Remember to include us in your workplace donations. Give frequently and happily. Give of yourself through volunteer service and always remember SCANCA, INC. Use our CFC # 57433 as often as you can. Thanks so much!!!

MESSAGE FROM THE EXECUTIVE DIRECTOR



Iola Y. Williams

Hello SCANCA, INC. Friends:

The year is passing rapidly. Sometimes I wonder how it goes so fast. However, we are not in control. Often we think we are, and then something wakes us up.

I have recently experienced a day of total blindness. It was not frightening but did cause a period of anxiety. This made me aware of how much we take our blessings for granted. I am sure most of us do that though we are not conscious of it. Hence, we must remember to always be aware of the many blessings we are privileged to.

Count your many blessings, name them one by one. Count your blessings see what God has done. Count your many blessing and it will surprise you what the Lord has done. Remember, to contribute to the blessings of others. Support SCANCA, INC. God bless you all!

TO SCANCA, INC. NEWSLETTER RECIPIENTS: PLEASE SEND YOUR EMAIL ADDRESS TO EMAIL@SCANCAINC.ORG SO WE CAN ECONOMICALLY GET THE NEWSLETTER TO YOU.

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.

MAKE A WISH FOUNDATION: The Make a Wish Foundation of the Mid-Atlantic, Inc. has a desire to service families and individuals with sickle cell disease. Those interested may contact Robyn Leenaerts at rleenaerts@midatlantic.wish.org. or call 1-877-599-9474.

SPRING EDUCATIONAL WORKSHOP
Siblings With And Without Sickle Cell
By Esther Agbaje

On May 1, 2010, SCANCA, INC. sponsored a workshop on Siblings of Children with Sickle Cell Disease: How can I make sure I'm attending to their needs? One of our newest members, Esther Agbaje and her brother, John, were joined by Dr. Edwin Powell, PhD., Adolescent Psychologist at Howard University, in discussing the subject. This workshop was well attended by both pediatrics and adults with interests that the whole family is working together.



Esther & John Agbaje



Dr. Edwin Powell, PhD.

Within a family, siblings can be the best thing or the worst thing. Siblings can be your best friend, or they can be the most annoying person in the room. When you are young they are an instant play mate, and when you are older they can be your most trusted confidante. At the same time, they are always invading your space and privacy. Either way, when you have a disease like sickle cell, siblings are often those you can count on to always make you feel better.

In a family dealing with sickle cell, the children who do not have sickle cell give a lot of their time and energy to make sure their siblings with sickle cell are comfortable and get better quickly. This can sometimes mean that the children without the disease may have to sacrifice events or activities that they want to do in order to accommodate their sibling when he or she gets sick. Since a large amount of the family attention is on the child who is sick, parents should take care not to create an environment where there are different expectations for a child with a disease and a child without. Dealing with sickle cell is a journey for the whole family, and not just one person.

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SPRING EDUCATIONAL WORKSHOP: Siblings With And Without Sickle Cell

In our family, we have children with and without sickle cell. This has allowed me to experience how to interact and share experiences with both of my brothers concerning the disease. We all are knowledgeable about the disease and know what has the potential to trigger crises, and how to take care of each other should a crisis occur. Our parents included us in the process, so no one would feel left out. They made sure that the disease did not become a point of resentment in our relationship as siblings.

My brother, John, spoke about what it is like to care for our youngest brother, Charles, or myself whenever we got sick. He talked about how our parents allowed him to take a responsible role in caring for us, if necessary. Many times he could be frustrated at the situation, especially when he does not have his brother as a playmate. He understood that this was part of our family and everyone had a role to play.

In a family with sickle cell or any other chronic disease, the illness is just one characteristic. Families are not built around an unfortunate circumstance, but rather built on love and support to thrive despite the disease. Parents who include the children without the disease in the caring of the children who get sick, can use the experience as an opportunity to explain to the child why their sibling is unable to keep them company. Parents should also be attentive to the needs of all their children, just as they are attentive to a child who is having a crisis. Siblings of people with sickle cell will probably feel some frustration with having a brother or sister who is sick, but if the children without the disease are made to feel as valuable members of the family, it adds to a healthy family dynamic.

Siblings share the same experiences, but with an illness like sickle cell, each person's experience is unique. My youngest brother, Charles, and I both have sickle cell, but our pain manifests in different ways. We do not feel the pain in the same way. A great benefit of both of us having sickle cell is that there is always someone to talk to who has experienced something similar, even if not the exact same way. We are role models for each other on how to get through the pain and continue living our lives to the fullest extent possible. We encourage each other and keep reminding each other that whatever pain we feel today, will soon pass.

Having a sibling without the disease is also beneficial because there is someone like you who is an example of how you can lead a normal life as possible. This person is like a personal cheerleader. This person also treats you normally, because they know you when you are sick and when you are well. They are able to support you in either capacity. My brothers are two of my best friends. I thank God for their love and support everyday, whether in dealing with sickle cell or any of life's other obstacles.

The doctor emphasized that some needs are more mental. If children get the love and care needed early in life, there will be less apprehension as they grow older. Sometimes the need to rush to a hospital is overemphasized. Instead, the individual needs to be made aware of the things that can be done at home and on a daily basis that will sometimes eliminate the need for hospital admission.

We left with a good feeling that everyone cares about our families and the need that it is the first and best medicine for all concerned.

HEALTH INFORMATION
10 REASONS YOUR BODY NEEDS WATER

1. Water helps to keep your skin moist and healthy.
2. Water helps maintain your body weight because it is a part of metabolism and helps to control your appetite. Replacing your beverages with water will save you lots of empty calories.
3. When you are properly hydrated you will have more energy.
4. Water may help to prevent headaches.
5. Drinking water aids in digestion and prevents constipation. It also helps to lower your risk of death from heart attacks.
6. Water helps to transport nutrients throughout your body. Certain vitamins can only function with water as a transport.
7. Water helps to flush out waste products from the body.
- 8 Drinking adequate water has been found to decrease the risk of colon and bladder cancers.
9. When you exercise you sweat out water and electrolytes. If you replenish the water loss after exercise, you will feel better.
- 10 You lose lots of water through your breathing. During times of exercise, anxiety or illness you breathe more rapidly and lose more water.

SIGNS AND SYMPTOMS OF DEHYDRATION

Little or no urination	Fatigue	Thirst	Muscle Weakness
Headache	Dry mouth	Lightheadedness or dizzy	

Be aware of increased **risks of dehydration** in the following circumstances:

Diarrhea	Vomiting	Fever
Sweating	Humid and hot weather	

SICKLE CELL COMMUNITY GETS INFORMATION THROUGH CHURCH SUPPORTED ACTIVITY

SCANCA, INC. is extremely thankful to Ms. Diane Pelt-Mansfield, Ms. Vivian Morgan and Rev. James Wiggins, Jr., Pastor of the Peace Lutheran Church at #15 - 49th Place, NE, Washington, DC, for their help and support as we celebrated World Sickle Cell Day. On June 19, 2010, many sickle cell individuals and community youth activists presented a concert with dance, song, instrumental selections, prayer and testimonies by several individuals with Sickle Cell Disease. They showed that "God is worthy to be praised." The generous gifts from those persons who attended are appreciated. SCANCA, INC. executive board and members are grateful to you.

CAMP FOR CHILDREN WITH SICKLE CELL

SCANCA, INC. Board Member, Cathy McCoy, coordinated our summer outreach to children with sickle cell. We were able to send 10 individuals to camp "Brainy Camps" for the 2010 summer. This year SCANCA, INC. partnered with the Children's National Medical Center to provide this excellent opportunity so that the children with sickle cell may have fun. Cathy is excited and we agree that this is a wonderful gesture. Hooray.....for SCANCA, INC. and CNMC. Thanks to each of you...and thanks to Cathy.

(Continued from Spring 2010 Newsletter, p.5)

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!!!

SCHOLARSHIP OPPORTUNITY

by Denise Garner

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 DC.). As part of its mission SCANCA, INC. strives to enhance education and other opportunities for persons living with sickle cell disease.

We recognize that in today's world education beyond high school is becoming a requirement to fill the employment opportunities of tomorrow. In these economic times paying for higher education can be challenging for most families. In keeping with its mission SCANCA, INC. offers a \$500.00 scholarship to high school graduates, with sickle cell disease, who are pursuing college or technical school and/or college students with sickle cell disease currently enrolled in an institution of higher learning.

If you are an individual with sickle cell or know an individual with sickle cell, who qualifies and can benefit from this scholarship opportunity, we invite you to apply for it or forward the attached application to that individual. The 2011 Scholarship Application is an attachment to this newsletter or you may go to our website: www.scancainc.org.

TRIVIAL -- THE OTHER STALL

Traveling down the interstate and needing to use the restroom, I stopped at a rest area and headed to the restroom. I was barely sitting down when I heard a voice from the other stall saying:
"Hi, how are you?"

I'm not the type to start a conversation in the restroom and I don't know what got into me, But I answered, somewhat embarrassed: **"Doin' just fine!"**

And the other person says: **"So what are you up to?"**

What kind of question is that? At that point, I'm thinking this is too bizarre so I say: **"Uhhh, I'm like you, just traveling!"??**

At this point I am just trying to get out as fast as I can when I hear another question: **"Can I come over?"**

Ok, this question is just too weird for me but I figured I could just be polite and end the conversation.. I tell them **"No. I'm a little busy right now!!!"**

Then I hear the person say nervously..."Listen, I'll have to call you back."

There's an idiot in the other stall who keeps answering all my questions

Cell phones, don't you just love them!!

____ 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](#)

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

SEPTEMBER IS NATIONAL SICKLE AWARENESS MONTH

UPCOMING EVENTS - 2010-2011

SUPPORT GROUP MEETINGS

Families Advocating for Children and Adults with Sickle Cell Disease (FACAS)
Fourth Saturday of EVERY month except November
(August 28; September 25; October 23; November 20, 2010) at 1:00: PM – 2:30PM
Howard University Hospital Cafeteria- Activity Room
Contact: Cathy McCoy on c:202-365-4501 or Esther Agbaje on c:757-651-2162

Stomp Out Sickle Cell (SOS) Walk - September 18, 2010
Freedom Plaza at Pennsylvania Avenue, NW. (between 13th and 14th Streets)
8:00AM - 12 Noon --- Registration at website: www.soswalk.org
For information call: 202-865-4445 or 1-866-322-3711 or
SCANCA, INC. contact bwharrison@Howard.edu or on 202-806-6329

Sickle Cell Disease Association of America, Inc. (SCDAA, INC.) 38th Annual Convention
September 21 - 24, 2010 -- Gaylord National Resort & Convention Center
201 Waterfront Street (National Harbor), Oxon Hill, Maryland 20745
Hotel Information: 301-945-2000; Convention Info: 1-410-528-1555 or 1-800-421-8453
Or email: scdaa@sicklecelldisease.org

Bone Marrow Transplant (BMT) Family Education Symposium
October 29 - 30, 2010 -- Children's National Medical Center
111 Michigan Avenue, NW., Washington, DC. 20010
Contact: Dr. Lewis Hsu at 202-476-5000 or 202-476-4572
Or at www.childrensnational.org

Christmas Party for the Sickle Cell Disease Community
December 11, 2010 - 12:00Noon - 3:00PM
UCFW 400 Building - Metro 400 - 4301 Garden City Drive, Hyattsville, Md. 20785
Metro transportation, New Carrollton exit (right)
Contact: Cathy McCoy on c:202-365-4501 or Esther Agbaje on c:757-651-2162

SCANCA INC. Executive business meeting
Plymouth Congregational Church, North Capital Street and Riggs Road, NW, Washington, DC
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



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Combined Federal Campaign #57433

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Website: www.scancainc.org -- email: email@scancainc.org

Education Toward The Management of Sickle Cell

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2011 Scholarship Application
Five Hundred Dollar (\$500.00) Scholarship
DEADLINE: JULY 30, 2011

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): _____

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).
6. Include a recent photo.

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

A member of Community Health Charities: Working for a Healthy America!

CFC 57433