SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC.

SCANCA, INC.

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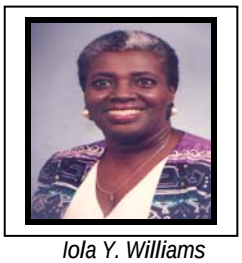
Sickle Cell Association of the National Capital Area, Inc. Is a 501 (c) (3) NONPROFIT, TAX EXEMPT ORGANIZATION

Volume 30 **SPRING 2017**

Education Towards The Management of Sickle Cell

MESSAGE FROM THE DESK OF THE EXECUTIVE DIRECTOR



Iola Y. Williams

I extend greetings to all on behalf of our Board of Directors. We thank you for the support you have given in the past. This past year has been an anxious yet exciting one. There have been much effort and assistance to improve the prognosis of sickle cell disease and our hope for the future.

SCANCA, INC. needs your support to fulfill its goals. With that support, our services will be able to continue and hopefully expand. Follow us on the website (www.scancainc.org) Participate in activities, read our newsletter and send us written items about your personal relationship with SCANCA, INC. and sickle cell disease. Help us to enlighten and educate others. Remember, knowledge is power!! We are here to serve YOU.

God bless you and we wish you a HAPPY 2017.

Iola Y. Williams, RN
Executive Director

REFRESH YOURSELF ABOUT SICKLE CELL

Many individuals with sickle cell disease can live for long periods without experiencing severe symptoms of the disease. Awareness and research of the disease, applications of therapies discovered through research studies, and improved use and availability of health care have contributed longer lives for individuals affected with sickle cell disease. Contrary to previous estimates, a large percentage of individuals with sickle cell disease survive beyond the age of thirty or even fifty years old.

Ideal practices and approaches to optimal care maintenance with sickle cell disease include “well-patient” care coupled with a positive outlook. This means that visits to the hematologist or primary healthcare provider doctor should not be isolated to “sick visits.” Well-patient medical follow-up visits provide a better psychological setting between the health provider and the family. Well visits help the medical caretaker to become familiar with the normal, healthy physical and laboratory studies. This should provide more effective health maintenance and preventive coping skills. Development of such relationships allows both the health care provider and the family to compile individualized information for better health maintenance and prevention.

HOW TO TALK SO YOUR DOCTOR WILL LISTEN
(From: Your Health – AARP Bulletin)

1. *MAKE A HUMAN CONNECTION* - Before you dive into your concerns, break the ice with a greeting or even a joke;

2. STAY ON MESSAGE – After the greeting, get to the point;

3. TELL THE WHOLE TRUTH – Tell your doctor about your fear of falling, substance abuse, sexual dysfunction or changes in sleep patterns;

4. REHEARSE BEFORE YOU GO – If you are uncomfortable discussing embarrassing topics, write a script and rehearse it in front of a mirror;

5. DON'T SAVE QUESTIONS FOR THE END – Once your doctor is halfway out the door, he/she is already thinking about the next concerns;

6. DON'T ACCEPT "IT'S JUST AGING' – If you have a symptom that has come suddenly be specific about the changes;

7. EXPLAIN WHAT YOU CAN AFFORD – If you cannot afford a prescription, ask your doctor for an alternative, or ask for help in prioritize medications and which ones are nonnegotiable;

8. HAVE THAT END-OF-LIFE DISCUSSION – Talk to your family and make sure your doctor is aware of your wishes. Make sure there is a document in your medical chart that spells out exactly what you want;

9. DO NOT GO IT ALONE – When going to see your doctor take someone with you to ensure that the doctor listens to you and answers your questions;

10. DO NOT BE AFRAID TO MAKE A SWITCH – If your doctor does not suit you, look for a new physician. There is no shame in finding someone who is a better fit.

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 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 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.

New Treatment for Sickle Cell Brings Hope and a Cure to Chicago Area Patients

Source Newsroom: University of Illinois at Chicago

Newswise — Two brothers have been cured of their sickle cell disease at the University of Illinois Hospital & Health Sciences System using a relatively uncommon type of stem cell transplant that is performed without chemotherapy. Their transplants were possible thanks to a third brother who was a match for both, against long odds.

Julius and Desmond Means never imagined life without sickle cell. The brothers, ages 25 and 19, have spent their lives in and out of hospitals, each suffering from different complications of the disease. Growing up, they tired easily and couldn't keep up with their friends. As they grew older, the disease caused bone damage and affected Julius's lungs. Desmond's organs were also being damaged, and he was jaundiced. For either young man to receive a transplant, a healthy sibling who is a compatible donor was needed. An acceptable match requires that at least eight of 10 known human leukocyte antigen (H.L.A.) genes be identical between donor and recipient.

Julius and Desmond's healthy older brother Clifford, 27, matched 10 of 10 H.L.A. genes with both of them -- an occurrence of "extremely low" likelihood, according to Dr. Damiano Rondelli, director of stem-cell transplantation at UI Health. The men's mother, Beverly Means, also noted the good fortune. "I had won the lottery of health," she said. In preparation for the transplant, Clifford was given medication to increase the number of stems cells released from the bone marrow into the bloodstream. His blood was then processed through a machine that collects white cells, including stem cells. The stem cells were frozen until the transplants.

Last May, Julius received his transplant at UI Hospital. He was given medication to suppress his immune system and one small dose of total body radiation right before the transplant. Then the frozen bags of stem cells were thawed and hung by IV pole for infusion into him. Then in September, Desmond received his stem cell transplant. Now several months since the transplants, both Julius and Desmond no longer have sickle cell disease. Their bone marrow is producing healthy red blood cells. "Being cured, I feel like we can do anything," says Julius, who composed a rap about his transplant while recovering in the hospital. The brothers are pursuing their interests in rap music and dance and plan to attend college.

The chemotherapy-free stem cell transplant is a new procedure and is much better-tolerated by patients with aggressive sickle cell disease, who often have underlying organ damage and other complications.

UI Health is the first center in the Chicago area to offer this treatment, and one other patient has been successfully transplanted here. The efficacy and safety of the pre-transplant medication regimen are currently being studied at UI Health. About 30 adults have received chemotherapy-free stem cell transplants for sickle cell disease at the National Institutes of Health in Bethesda, Md. Approximately 85 percent have been cured.

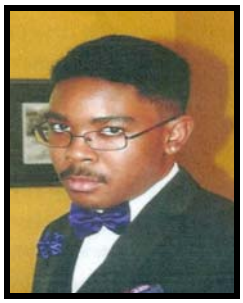
Join the Marrow Registry – transplant frees the sickle cell sufferer from pain. You only have to be between the ages of 18 and 60, be willing to donate to any patient in need, and meet the health guidelines. A cheek swab is all it takes to see if you are a match to help save the PRECIOUS GIFT OF LIFE.

BE A BLOOD DONOR – BE THE ANSWER TO THE PROBLEM!
FOR INFORMATION: 1(800)MARROW-2BETHEMATCH.ORG

SCANCA, INC. AWARDS THREE SCHOLARSHIPS IN 2016

By Denise Garner

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.) It is part of SCANCA, INC'S mission to enhance the education of persons with sickle cell disease by providing a ($500.00) Five Hundred Dollar scholarship for students enrolled in institutions of higher learning; e.g., college, technical school or graduate school.

If you are a sickle cell individual who is a Rising Freshman, an Upperclassman, a Graduate student or student pursuing technical education, we would love to assist you in the pursuit of your education. Former recipients may reapply. An application is enclosed in this newsletter or you may apply at our website (www.scancainc.org or from your social worker at your medical facility.

The 2017 application deadline is June 30, 2017. All documents must be enclosed and received by the deadline. We look forward to hearing from you!

HEALTH TIPS

Warm weather is coming!! 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, Drink, 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.**

2016 CHRISTMAS CELEBRATION

On December 3, 2016, SCANCA, INC. held its annual Holiday Party for families affected with sickle cell disease. Santa's visit was the highlight as he delivered plenty toys to the children present. About 100 people joined together for a delicious holiday luncheon and to fellowship with each other. Families battled to win prizes and guess how much was in the money jar. Music, by our DJ, was at its best.

Special thanks go to the organizations that made it happen: the Top Ladies of Distinction and Top Teens. Prince George's County Chapter; the Sassy Seasoned Sisters; Howard University Center for Sickle Cell Disease; the Christopher Gipson Sickle Cell Moya Moya Foundation; and Faces of our Children.

SUMMER CAMP

Parents: Are you interested in sending your child/children to summer camp? Just let your social worker know and have that person contact the Sickle Cell Association of the National Capital Area, Inc. (SCANCA, INC.) . The camp scholarships can only be processed through your health care institution.
DON'T WAIT TOO LATE!!

EVERYONE SHOULD DRINK PLENTY OF WATER!!

TRIVIAL

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BOOKBAG
BOOKS
BUS
HOMEWORK
MATHEMATICS
MUSIC
SCISSORS
TARDY
TEACHERS
ERASER
GLUE
GRADES
RECESS
RULER
SHARPENER
DETENTION
DICTIONARY
ENGLISH
PENS
PRINCIPAL
PTA
CALCULATOR
COMPUTER
CRAYONS
NOTEBOOK
PAPER
PENCILS

FIRST PATIENT IN PHASE 3 HOPE STUDY IN SICKLE CELL

Global Blood Therapeutics Announces Enrollment of First Patient in Phase 3 HOPE Study in Sickle Cell Disease SOUTH SAN Francisco, Calif. – January 17, 2017 – Global Blood Therapeutics, Inc. (GBT) (NASDAQ:GBT) today announced enrollment of the first patient in the HOPE (Hemoglobin Oxygen Affinity Modulation to inhibit Hbs PolymErization) Study, a pivotal Phase 3 clinical trial of GBT440 in people with sickle cell disease (SCD). The HOPE Study will be conducted at leading SCD sites globally and is expected to enroll up to 400 adults and adolescents with SCD who have had at least one episode of vaso-occlusive crisis (VOC) in the previous year. "Enrolling the first patient in our pivotal Phase 3 HOPE Study is an important milestone for GBT as we continue to work to bring GBT 440 to the SCD community," said Ted W. Love, M.D., president and chief executive officer of GBT. "The innovative HOPE Study trial design has strong grounding in the mechanist of action of GBT 440 and is designed to assess the efficacy of GBT 440 in producing meaningful clinical improvements in anemia and daily symptoms. GBT 440 has the potential to fundamentally modify the course of this devastating disease by habiting sickle hemoglobin polymerization, the fundamental cause of SCD pathophysiology.

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 – 2017

SCANCA, INC. ANNUAL SPRING WORKSHOP

Saturday, May 6, 2017 - 12 Noon - 2:00 pm
8400 Corporate Drive, Landover, Maryland 20785
First floor, Activity Room
RESERVATIONS NEEDED: rsvp@scancainc.org
For Info: 202-271-5733

MARYLAND STATE SICKLE CELL PICNIC

For info: Kim Miller 410-955-6132

SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA)

Walk With The Stars!
On August 26, 2017 team up with SCDAA
and kick off the 2017 Walk with the Stars.
Whether you walk, jog, or run, just be sure to join us for the only 5K race
that benefits sickle cell disease on a national level.
ALSO
Annual Convention (SCDAA)
For info: Office: 1-410-528-1555 - or 1-800-421-8453

SCANCA INC. Executive business meeting
Third Saturday each month– except July and August
Onsite and/or teleconference - call in advance (202-271-5733)

SCANCA, INC. 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

P.O. BOX 41479
WASHINGTON, DC. 20018-0879