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 34 **FALL/WINTER 2018**

Education Towards the Management of Sickle Cell

MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT


Iola Y. Williams

Hello Friends:

I take this time to thank you for your support of the Sickle Cell Association of the National Capital Area, Inc. and in serving the Sickle Cell community. Most importantly, I express my sincere gratitude to our Board of Directors, some who have served since our inception, without whom the hard and sometimes tedious glories would not be realized. The continuous, supportive, and collaborative efforts of all surely help us to blossom.

SCANCA, INC. reached many goals in our community. We have contributed through our financial assistance for our qualified high school graduates with $500.00 scholarships. In 2016 there were three scholarship recipients and in 2017 there were five scholarship recipients. This year we have two recipients. Assistance is also given in times of family hardship in evictions, bereavement, utilities and other urgent needs. We support research in Sickle Cell Disease by providing Educational workshops and inspirational programs. There is no doubt that with your support and encouragement SCANCA, INC. will continue to flourish with medical, social research and financial services to the Sickle Cell Community.

God bless each of you!

Iola Y. Williams

SEPTEMBER IS NATIONAL SICKLE CELL MONTH

SCANCA, INC. SERVES THE COMMUNITY

During the year members of SCANCA, INC. participate in many community and government agency health fairs. This year we were represented at the First Baptist Church of Glenarden, Maryland; Ft. Washington, Md.; U. S. Department of Housing and Urban Development (HUD) in Washington, DC. and others.

At these opportunities we distribute health news and SCANCA, INC. newsletters giving needed information on health and community issues. Our scholarship awardees are shown as incentive to the youth of the sickle cell community. Personal stories are sometimes inserted to reflect that the sickle individual is not alone. Recent innovations and discoveries are giving the newest services and medications to the sickle cell individuals through many research efforts. We encourage the use of this application for all sickle cell individuals above the high school level. This is a timely opportunity. Trivia, on page 6, is the fun part of this newsletter. We encourage you to read every word and let us know what you think. Just call or email us. We need to hear from you.

Discussing the sickle cell complication of priapism

Priapism is a nonsexual painful erection of the penis, due to blood sickling in the penis.

This can occur in males with sickle cell disease, even boys before puberty. Priapism often occurs in the early morning hours.

Home care suggestions:

1. Drink more fluids;
2. Elimination of fluids (Urinate);
3. Do mild exercise such as walking or climbing stairs;
4. Try a warm cloth or warm soak in a bathtub.

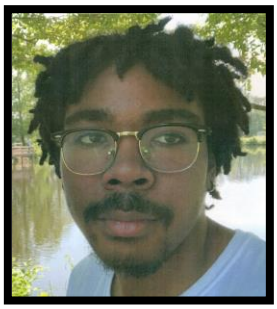
An episode of priapism that does not resolve in about 30 m;inutes should be evaluated in the emergency room for

1. Intravenous fluids
2. Pain medicine
3. Urology penile aspiration might be needed as an emergency procedure.

Treatment goals for priapism are to decrease pain and avoid scarring in the penis with problems for adult erectile function.

SCANCA, INC. 2018 SCHOLARSHIP AWARDEES

ERICA QUAN



XAVIER RAY

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 Five Hundred Dollar ($500.00) scholarship for students enrolled in institutions of higher learning e.g. college, technical school or graduate school.

The 2018 SCANCA, INC. scholarship awardees are Erica Quan and Xavier Ray. Both are prior SCANCA, INC. awardees. Erica Quan has completed her sophomore year at Stevenson University where she is majoring in Pre-Med, She aspires to be a Physician. Xavier Ray is a returning student at Morgan State University majoring in Computer Science. He aspires to be a Criminal Investigator.

If you are a sickle cell individual who is a Rising Freshman, an Upperclassman, a Graduate student or student pursuing a technical education, we would love to assist you in the pursuit of your education. Former recipients may reapply. A SCANCA, INC. scholarship 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 2019 application deadline is June 30, 2019. All documents must be enclosed and received by the deadline. We look forward to hearing from you!

SICKLE CELL NEWS

Therapy with L-Glutamine reduces pain in patients with sickle cell disease

https://www.ucsf.edu/news/2018/07/411221/new-study-shows-l-glutamine-decreases-sickle-cell-pain-crises-hospitalizations

CSF Benioff Children's Hospital Oakland clinical researchers, in conjunction with other sickle cell centers and scientists at Emmaus Life Sciences, Inc., have demonstrated that therapy with L-Glutamine reduced the frequency of pain episodes in both pediatric and adult patients with sickle cell disease (SCD). The results of the 48-week, phase 3 clinical trial are published in the July 19, 2018, issue of *New England Journal of Medicine*.

The paper, "A Phase 3 Trial of L-Glutamine in Sickle Cell Disease," documented the effects of taking Endari™, a prescription-grade, pharmaceutical form of L-glutamine, as compared to placebo, for 230 patients aged 5 to 58 years of age with sickle cell disease. Endari™ was approved in July 2017 by the U.S. Food and Drug Administration based on the safety and efficacy data from this study. Glutamine is an amino acid that is involved in several biochemical reactions.

Continues on page 4 L-Glutamine in Sickle Cell Disease

Continued from page 3 L-Glutamine in Sickle Cell Disease

The study showed that whether administered alone or with hydroxyurea, L-glutamine reduced the frequency of sickle cell pain crises by 25 percent (a median of three events per patient in the L-glutamine group and four in the placebo group) and hospitalizations by 33 percent (a median of two hospitalizations in the L-glutamine group and three in the placebo group). Additional findings showed lower cumulative hospital days of 41 percent and a lower incidence of dangerous acute chest syndrome (ACS) by more than 60 percent.

“This study validated research on the safety of pharmaceutical grade L-glutamine which has antioxidant properties that improves the NAD redox potential in sickle cell patients. Safe neutraceuticals are of major importance to the sickle cell community,” said Elliott Vichinsky, MD, Director of Hematology/Oncology at the Northern California Sickle Center at UCSF Benioff Children’s Hospital Oakland. “Our clinical trial found that L-glutamine, which does not require any routine laboratory monitoring, decreases pain events in patients by itself or in combination with hydroxyurea. It is a major advance in therapy for sickle cell disease and offers families safe, new therapeutic options.”

Sickle cell disease is a genetic blood disorder that causes a distortion in the shape of red blood cells. This leads to the many symptoms and medical problems affecting children and adults with sickle cell disease, including pain, anemia, and bone, kidney, lung and neurologic problems.

“Endari, is the first approved treatment for sickle cell disease in pediatric patients 5 years of age and older and the first in nearly 20 years for adults,” said study co-author Yutaka Niihara, MD, CEO and founder of Emmaus, which produces the product. “Our hope in sharing the results of this data from the *New England Journal of Medicine* is to increase awareness of sickle cell disease, a lifelong hereditary blood disorder which commonly affects those of African descent, as well those from Central and South America and people of Middle Eastern, Asian, Indian and Mediterranean descent. It is important for patients to know that they have a treatment option for this debilitating disease.”

The double-blind trial evaluated the efficacy and safety of pharmaceutical-grade L-glutamine administered twice daily by mouth, as compared with placebo, in reducing the frequency of pain crises among patients with sickle cell anemia or sickle β^0-thalassemia and a history of two or more pain crises during the previous year. Patients who were receiving hydroxyurea at a dose that had been stable for at least 3 months before screening continued that therapy through the 48-week treatment period.

Patients were randomly assigned, in a 2:1 ratio, to receive L-glutamine (152 patients) or placebo (78 patients). Those in the L-glutamine group had significantly fewer pain crises than those in the placebo group ($P = 0.005$) and fewer hospitalizations ($P = 0.005$). Approximately 54 percent of the patients were female and 66 percent of the patients in both trial groups were already receiving hydroxyurea. The study found that low-grade nausea, non-cardiac chest pain, fatigue and musculoskeletal pain occurred more frequently in the L-glutamine group than in the placebo group. Funding for this trial was provided by Emmaus Life Sciences, Inc.

Study authors for the Phase 3 Trial of l-Glutamine in Sickle Cell Disease include Yutaka Niihara, M.D., M.P.H., Emmaus Medical, Torrance and University of California at Los Angeles; Scott T. Miller, M.D., State University of New York-Downstate Medical Center; Julie Kanter, M.D., Medical University of South Carolina, Charleston; Sophie Lanzkron, M.D., M.H.S., Johns Hopkins Hospital, Baltimore; Wally R. Smith, M.D., Virginia Commonwealth University Healthcare Systems, Richmond; Lewis L. Hsu, M.D., Ph.D., Victor R. Gordeuk, M.D., University of Illinois at Chicago, Chicago; Kusum Viswanathan, M.D., Brookdale University Hospital and Medical Center; Sharada Sarnaik, M.D., Children’s Hospital of Michigan, Detroit; Ifeyinwa Osunkwo, M.D., Carolinas HealthCare System, Charlotte, NC; Edouard Guillaume, M.D., Interfaith Medical Center; Swayam Sadanandan, M.D., Brooklyn Hospital Center; Lance Sieger, M.D., Osbourne A. Blake, M.D., Los Angeles, Kaiser Permanente Medical Center, Inglewood; Joseph L. Lasky, M.D., Eduard H. Panosyan, M.D., Harbor–UCLA and Los Angeles BioMedical Research Institute; Tamara N. New, M.D., Children’s Healthcare of Atlanta, Emory University, Atlanta; Rita Bellevue, M.D., New York Presbyterian Brooklyn Methodist Hospital; Lan T. Tran, M.P.H., Rafael L. Razon, M.D., Charles W. Stark, Pharm.D., Emmaus Medical, Torrance; Lynne D. Neumayr, M.D., and Elliott P. Vichinsky, M.D., UCSF Benioff Children’s Hospital Oakland Research Center, Oakland.

More Scientific News for the Sickle Cell Anemia Community

How Yogurt Science Could Lead To A Cure For Sickle Cell Anemia
http://www.wbur.org/commonhealth/2017/04/28/yogurt-sickle-cell-anemia

The discovery of CRISPR and gene editing was not made by a geneticist or a stem cell biologist. CRISPR was discovered by a bunch of microbiologists, scientists who study bacteria and viruses.

In fact, much of the foundational work in CRISPR was done by nutritional microbiologists who wanted to understand how the bacteria we use to make cheese and yogurt are able to fight off viral infections. Imagine that! The future of gene therapy began in a yogurt vat.

New Pain Protocol Cut Time to Treatment in Sickle Cell Kids
Using intranasal fentanyl instead of oral morphine cut delays
https://www.medpagetoday.com/meetingcoverage/additionalmeetings/64948

Switching from an oral morphine protocol to intranasal fentanyl for children with sickle cell disease and vaso-occlusive crisis significantly reduced the time to first analgesia -- an indicator of improved care quality, researchers said here.

A chart review of 107 pediatric sickle cell patients treated at the Centre Hospitalier Universitaire Sainte-Justine here, covering two six-month periods before and after the protocol change, showed the time from patient registration to first opiate dose decreased by 46 minutes, reported Yves Pastore, MD, co-director of the hospital's sickle cell disease program and assistant professor at the Université de Montréal here, at the American Society of Pediatric Hematology/Oncology's annual meeting.

Remember a few years ago when your friends were pouring buckets of ice cold water over the heads in the name of science? In total, a whopping $220 million was raised from the challenge to help from 12,000 to 15,000 people in United States who reportedly live with Amyotrophic Lateral Sclerosis.

But did you know that sickle cell anemia is the single most common life-threatening genetic disease in the United States? Over 100,000 Americans suffer from sickle cell disease and it is a torturous, painful life to live. Yet, the funding and publicity of sickle cell disease lags drastically far behind that of virtually every other genetic illness.

COLD WEATHER PRECAUTIONS FOR SICKLE CELL DISEASE INDIVIDUALS

It is imperative that precautions are practiced to preserve a healthy body. Prolong exposure to cold temperatures can adversely affect the health of persons affected with Sickle Cell Disease. Remember, cold temperatures cause the blood vessels to become smaller or more constricted. This prevents the blood from flowing freely causing the sickle cells to more readily clog the small blood vessels. Here is a list of things that you must keep in mind during the cool and cold months:

- O Dress for the weather. Wear layers of clothing to enhance warmth and that can be easily removed when too warm. Prevent prolong exposure to the cold temperatures, wear hats (heat is lost through the head), gloves and leg coverings.

- O Practice slow, deep breathing to keep the lungs well oxygenated. Well-oxygenated lungs aid in promoting more oxygen to the block cells, which prevents sickleing.

- O Maintain physical activity. Activity renders you less susceptible to acute chest syndrome and pneumonia.

- O Continue to drink lots of water. You can become dehydrated even in the cold months.

- O Maintain healthy dietary habits. This helps to protect your body for those days when you can not eat well because of illness.

- O Take warm baths to stimulate your circulation and massage painful or achy areas. Remember, look at any area that is painful, every pain is not necessarily associated with Sickle Cell. There could be an injury or other causes.

- O Inform your medical caretaker if you develop a persistent cough, fever, and severe or prolong pain.

- O Remember to especially keep young children comfortably warm.

BEWARE: Anything that affects your body temperature adversely has the capability of affecting your health and well being. Contact your Healthcare Provider if you have any concerns. Follow your providers advice.

NOTE: WORDS WILL APPEAR DIAGONALLY, HORIZONTAL, VERTICAL, and BACKWARDS

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

FIND:

COMMUNITY	HEALTH	LEARNING	PLANNING	VOLUNTEERS
DOCTOR	HOPE	LOVE	RESEARCH	
EDUCATION	HOSPITAL	MEDICAL	SERVICE	
EMERGENCY	JOY	MEETING	SICKLECELL	
GENETICS	KNOWLEDGE	NURSE	SUPPORT	

Place the unused letters (first 8 rows) in order in the blank spaces below to write out an important message.

Puzzle answer on page 7

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(SCANCA, INC.)

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

Send donations through Paypal.com to: email@scancainc.org

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

SCANCA, INC. IS NO LONGER ASSOCIATED WITH CFC

PUZZLE ANSWER: SEPTEMBER IS SICKLE CELL AWARENESS MONTH

EVERYONE SHOULD DRINK PLENTY OF WATER!!

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

UPCOMING EVENTS – 2018

ANNUAL CHRISTMAS PARTY
Saturday, December 1, 2018 - 12n – 2pm
8400 Corporate Drive - Landover, Md. 20785
first floor meeting room
RESERVATIONS NEEDED – rsvp@ scancainc.org
202-271- 5733 for information

ANNUAL STOMP OUT SICKLE CELL WALK
September 8, 2018
For Information: www.soswalk.org

Sickle Cell Disease Association of America, Inc.
46th Annual National Convention

October 10-13, 2018
Hyatt Regency Baltimore Inner Harbor
Baltimore, Maryland
1-800-421-8453

SCANCA, INC. SUPPORT GROUP NEEDS LEADERSHIP AND SUPPORT
Let us know if you would like to assist in this effort.
Call SCANCA, INC., at 202-271-5733

SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING
Available by appointment only.
Call SCANCA, INC., at 202-271-5733

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