SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC.

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

Volume 31 **FALL 2017**

Education Towards the Management of Sickle Cell

FROM THE DESK OF THE EXECUTIVE DIRECTOR

Iola Y. Williams

Hello Friends,

SCANCA, INC's Board of Directors loves the work we have been able to do for the past 23 years. However, we are now struggling to continue due to a significant decrease in financial donations. We know that you care and we are grateful for your assistance. Please look into your hearts and consider the extent to which you can open more for the sickle cell community.

I remind you of our mission: to provide programs that **educate** the National Capital Area Community about Sickle Cell Disease, and to utilize effective resources that **benefit the lives** of individuals with Sickle Cell Disease, their families, and communities. These goals are done through our **Counseling and Referrals, Advocacy, Research Support, Partnership,** and **Service. Service** is one of our most significant missions. It includes assistance with **medical bills, funerals/burials, scholarships, utilities, rent/mortgage,** and others**.** Our community needs have been enormous, yet our financial support is shrinking. We need everyone, especially **YOU**! See page 7 for ways you can donate.

I pray that God continues to give us the faith and strength to continue.

God Bless,
Iola Y. Williams

SCANCA WORKING IN THE COMMUNITY

Beverly Ames works in the community

On Thursday, May 25, 2017, Board member Beverly Ames represented SCANCA, INC. for Health Week 2017 at The SEED Public Charter School, 4300 C Street, SE, Washington, DC 20019. Approximately 50-75 students and teachers visited her table for education and information.

Throughout the year, SCANCA, INC. members are out in the community at health fairs, seminars and workshops, where hundreds of persons receive our supplies and information.

SEPTEMBER IS NATIONAL SICKLE CELL AWARENESS MONTH!

FDA **APPROVES NEW TREATMENT FOR SICKLE CELL DISEASE**

First approval for this rare blood disorder in nearly 20 years

The U.S. Food and Drug Administration approved Endari (L-glutamine oral powder) for patients age five years and older with sickle cell disease to reduce severe complications associated with the blood disorder.

"Endari is the first treatment approved for patients with sickle cell disease in almost 20 years," said Richard Pazdur, M.D., acting director of the Office of Hematology and Oncology Products in the FDA's Center for Drug Evaluation and Research and director of the FDA's Oncology Center of Excellence. "Until now, only one other drug was approved for patients living with this serious, debilitating condition."

The safety and efficacy of Endari were studied in a randomized trial of patients ages five to 58 years old with sickle cell disease who had two or more painful crises within the 12 months prior to enrollment in the trial. Patients were assigned randomly to treatment with Endari or placebo, and the effect of treatment was evaluated over 48 weeks. Patients who were treated with Endari experienced fewer hospital visits for pain treated with a parenterally administered narcotic or ketorolac (sickle cell crises), on average, compared to patients who received a placebo (median 3 vs. median 4), fewer hospitalizations for sickle cell pain (median 2 vs. median 3), and fewer days in the hospital (median 6.5 days vs. median 11 days). Patients who received Endari also had fewer occurrences of acute chest syndrome (a life-threatening complication of sickle cell disease) compared with patients who received a placebo (8.6 percent vs. 23.1 percent).

Common side effects of Endari include constipation, nausea, headache, abdominal pain, cough, pain in the extremities, back pain and chest pain.

Endari received Orphan Drug designation for this use, which provides incentives to assist and encourage the development of drugs for rare diseases. In addition, development of this drug was in part supported by the FDA Orphan Products Grants Program, which provides grants for clinical studies on safety and/or effectiveness of products for use in rare diseases or conditions.

The FDA granted the approval of Endari to Emmaus Medical Inc.

SCANCA, INC. 2017 SPRING WORKSHOP



SCANCA, INC. board members Cathy McCoy and Barbara Harrison did a tremendous job planning and executing the Spring Workshop, May 6, 2017, from 12:00pm – 2:00pm at 8400 Corporate Drive, New Carrollton, MD. The two speakers were Denise Garner, Social Worker, Georgetown University Medical Center and Lisa Davies, Social Security Administration Consultant. Each was very knowledgeable and informative of their subject matter which initiated a lively questions and answers session. Guests included members from the Health Ministry at Zion Baptist Church, Washington, DC. The caterer, Dietrich Ames, owner of D & Hawks Hands Catering, served a delicious healthy lunch.

Beverly Ames, Reporter

CARE TRANSITIONS FOR EMERGING ADULTS WITH SICKLE CELL DISEASE.

Thanks to the sickle cell community for participating in the "Management of Sickle Cell Disease" workshop hosted by the Patient-Centered Outcomes Research Institute (PCORI). Based on the results of the meeting, we would like to inform you that PCORI will be releasing a new funding announcement titled, "Management of Care Transitions for Emerging Adults with Sickle Cell Disease." The goal of this announcement is to support patient-centered clinical effectiveness research (CER) that focuses on comparing the effectiveness of established transition coordination models for emerging adults (e.g., 16-25 years of age) with sickle cell disease transitioning from pediatric to adult care. Up to $25 million in total costs will be available to support up to three (3) studies in this area. The mission of PCORI is to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions.

Young adults with sickle cell anemia are at high risk for increased hospitalization and death at the time of transition to adult care. This may be related to failure of the transition system to prepare young adults for the adult healthcare system. This qualitative study was designed to identify factors related to transition that may affect the health of adults with sickle cell anemia.

PROCEDURE: Ten patients currently treated in an adult hematology clinic participated in semi-structured qualitative interviews to describe their experience transitioning from pediatric to adult care and differences in adult and pediatric healthcare systems.

RESULTS: Participants were generally unprepared for the adult healthcare system. Negative issues experienced by participants included physician mistrust, difficulty with employers, keeping insurance, and stress in personal relationships. Positive issues experienced by participants included improved self efficacy with improved self care and autonomy.

CONCLUSIONS: In the absence of a formalized transition program, adults with sickle cell anemia experience significant barriers to adult care. In addition to medical history review and identification of an adult provider, transition programs should incorporate strategies to navigate the adult medical system, insurance and relationships as well as encouraging self efficacy.

TRIVIA

Some words mimic the sounds they make. We've hidden 25 of them in the grid, reading across, down and diagonally. When you've found them all (minus the hyphens), the leftover letters will reveal a song lyric that might sound familiar.

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

ACHOO
BANG
BOING
BOOHOO
CHOO-CHOO
CLICKETY-CLACK
CLINK
CLUCK
DING-DONG
GULP
HONK
KABOOM
KERPLUNK
PITTER-PATTER
PLOP
POW
SLURP
SPLASH
SQUISH
SWOOSH
THWACK
TICK-TOCK
TSK-TSK
VROOM
ZING

Solution on page 6

MANDATORY TESTING FOR PROFESSIONAL ATHLETES (Update)

Dr. Biree Andemariam, SCDAA's Chief Medical Officer interviewed with the ***Bleacher Report*** to discuss SCDAA's position on mandatory testing for NCAA and NFL players.

Since 2010, the Sickle Cell Disease Association of America (SCDAA) has maintained its position that "screening athletes for sickle cell trait and subjecting carriers to alternative training regimens, as recommended by the National Collegiate Athletic Association (NCAA) and National Athletes Trainer's Association (NATA), has not been demonstrated to reduce the incidence of training-related deaths. Nevertheless this approach carries great risk of stigmatization and discrimination against athletes with sickle cell trait. The NCAA mandate for sickle trait screening does not provide adequate assurance of the privacy of genetic information nor protection from the discriminatory use of such information.

The SCDAA supports the implementation of universal, safe training guidelines *for all athletes*, and to rigorously educate and improve the capacity of athletic coaches and trainers to recognize signs and symptoms of heat related illness and to provide medical care to athletes who become ill or injured under their supervision."

SCANCA, INC. 2017-2018 SCHOLARSHIP AWARDEES


Kaitlyn L. Adams


Austin Walker


Candace Poullard


Paul Williams, Jr.


Priscilla Malone

As part of SCANCA INC's mission to enhance the education of persons with sickle cell disease. We do this by providing scholarships to students enrolled in institutions of higher learning (e.g.: college, technical school or graduate school).

In 2017, SCANCA, INC. awarded scholarships of $500 to five applicants - all of whom were high school seniors in their respective schools. Each of the candidates has faced a challenging course with their medical conditions, yet all have remained determined not to allow their medical situation to determine the direction of their lives. The candidates faced adversity with optimism and a "can do" spirit. While not always able to attend school, they view education as a stepping stone to their future and maintained a strong desire to excel academically.

Kaitlyn Adams will be attending Morgan State University in Baltimore, Maryland where she plans to major in Social Work. She would like to continue her education by ultimately obtaining a Masters degree and hopes to one day work as a Clinical Social Worker in the area of Pediatric Hematology/Oncology. She states, "it is my passion to use my career to ensure that sick children everywhere get the support and care they need while battling illnesses."

Austin Walker will be attending Johnson C. Smith University in Charlotte, North Carolina where he plans to major in Engineering. He hopes to obtain both a Bachelor and Masters degree in his chosen field. Austin has overcome many medical challenges to achieve his goal. He states, "even with my health struggle through high school, my aspiration to be a college graduate is bigger than I ever thought." He recognizes that while his struggles will continue, he is prepared to give it his best.

Candace Poullard will be attending Towson University located in Towson, Maryland. She plans to major in Secondary Education with a minor in World History. She developed a passion for World History in Middle School and subsequently developed a passion for teaching thus combining the two. Candace learned to advocate for herself as a result of her medical condition and has a desire to advocate for others. She states that, "my passion for helping people led me to set a goal for myself to better my community and give a voice to those that don't have one."

Paul Williams, Jr. will be attending Frostburg State University in Frostburg, Maryland where he plans to major in Biology. A summer of severe illness influenced Paul's decision to pursue a career in medicine. He has volunteered with the Center for Sickle Cell Disease at Howard University and taken classes in math and science in preparation. Paul states that, "the most valuable lesson that I have learned is that through sheer determination and hard work I have the power to make all things happen."

Priscilla Malone will be attending Virginia State University in Petersburg, Virginia where she will major in Biology. She would like to become a Genetic Counselor and hopes to educate and counsel individuals and families about inherited medical diseases. Priscilla has shared that, "though Sickle Cell Disease can be a painful and unpleasant challenge, it has at the same time been my greatest motivator for wanting to excel in my studies, my strongest reminder to love and value those closest to me, and my greatest reason to have hope and push for my dreams."

We salute the efforts and courage of all our recipients to overcome great medical challenges, yet excel in their academic work and remain focused to achieve their goals. We wish them much success in their future endeavors.

The SCANCA, INC. Scholarship is available to students attending technical school, community college, four year university or college and graduate or professional school. If you are interested in applying please complete the enclosed application or visit our website at www.scancainc.org. We look forward to hearing from you for the 2018-2019 academic year!

LIVING WITH SICKLE CELL DISEASE: MY STORY

by DeShon Eason

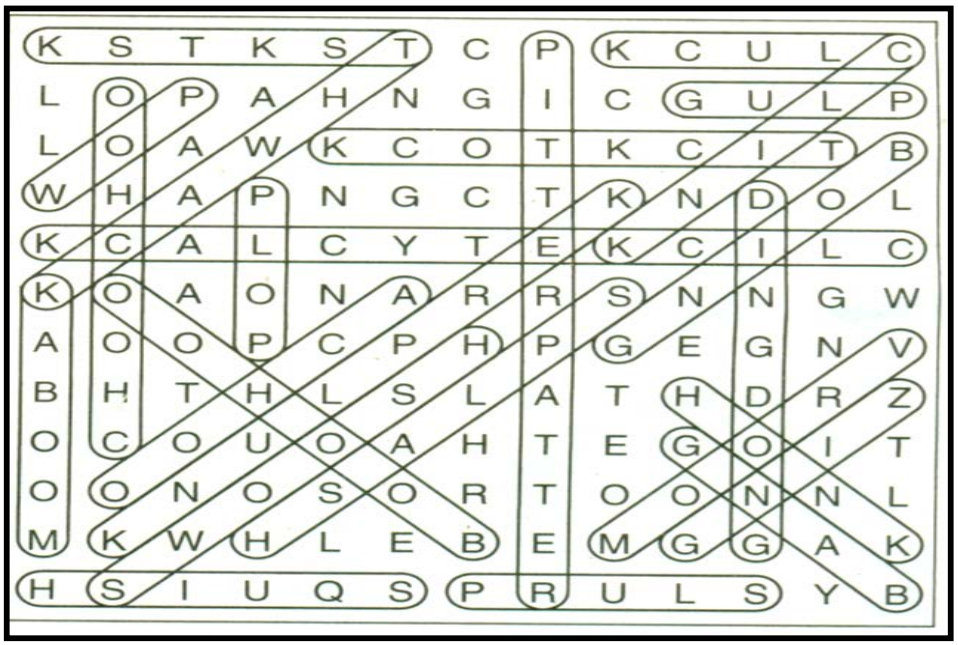
Being an active child, I lived for the summers of riding my bicycle and jumping double dutch with friends in the alleyways of DC. Unfortunately, being diagnosed with Sickle Cell Anemia (SCA) often limited me from fully participating in activities at times. My mother recognized my love for the outdoors and with the knowledge she had about SCA, she pushed hydration and a daily vitamin routine (i.e. folic acid, magnesium and cod liver oil), to keep my siblings and me as healthy as possible. Yet she, for as much research as she did on her own on SCA, was at a lost for managing the health of my sister and me, who were both diagnosed with Sickle Cell Disease at birth.

With month long recurrent hospitalizations through my adolescent years, I could not help but feel different from others, despite every attempt by my mother to remind me that I could meet anything I achieved. I continued to feel that a diagnosis of SCA would always limit me physically, and that I may never be able to live a 'normal' life. Luckily, with the added care of my Pediatrician, Dr. Karl Hammonds and eventually Nurse Practitioner Iola Williams, my mother's focus on wellness and preventive care decreased the number of crises I experienced over the years.

By being afforded the opportunity of having progressive professionals in my life at a young age, I have been blessed to not have been challenged severely, by this disease in my adult life. Having models, like my mother, Olivia Eason, who have now passed, and Ms. Williams, I was built up psychologically, spiritually, and physically to endure a time where research for SCA was lagging. I am now a Physical Therapist who assists individuals in restoring function after a crisis or post hip replacement due to bone death, commonly seen in patients with a diagnosis of SCA.

Answer to the puzzle on page 4

Leftover letters spell: CLANG, CLANG, CLANG WENT THE TROLLEY (from “The Trolley Son,” as sung by Judy Garland in Meet Me in St. Louis).



SUPPORT THE
SICKLE CELL ASSOCIATION OF THE NATIONAL CAPITAL AREA, INC.
(SCANCA, INC.)

Please mail your financial support to: **SCANCA, INC.**
P.O. Box 41479
Washington, DC 20018-0879

Send donations through **Paypal.com** to: **Email@SCANCAinc.org**

NOTE: To enhance our newsletter, we need your assistance.
Please write an article about your life with sickle cell, and how you or a family member have coped. Include your name, address, email, telephone number, and a picture, if possible. Also state your permission for us to print your article in our newsletter.

PLEASE EMAIL YOUR SUBMISSION TO: **Email@SCANCAinc.org**

_____ 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 – 2017

MARYLAND STATE SICKLE CELL PICNIC
Saturday, September 30, 2017 - 12:00 PM TO 4:00 PM
Druid Hill Park: Chinese Pavilion (NEW LOCATION)
Corner of Swann Drive & Beechwood Drive, Baltimore MD 21217
RSVP by September 26, 2017 to: Kim Miller 410-955-6132
Press option 2 (5 guests per sickle cell individual)
FREE FOOD AND ENTERTAINMENT (Bring blanket and chair)

45TH ANNUAL CONVENTION OF SICKLE CELL DISEASE ASSOCIATION OF AMERICA (SCDAA)
"Going Beyond - Overcoming Challenges and Celebrating Victories in the SCD Community."
October 25-28, 2017 Atlanta, GA
Contact: SCDAA Office: 410-528-1555 or 800-421-8453
scdaa@sicklecelldisease.org | http://sicklecelldisease.org

SCANCA, INC. ANNUAL HOLIDAY PARTY
CALL SCANCA, INC. AT 202-271-5733 for information
FOLLOW THE WEBSITE – Must RSVP for entrance

SCANCA, INC. EXECUTIVE BUSINESS MEETING
Plymouth Congregational United Church of Christ
5301 North Capitol Street, NE, Washington, DC 20011
Third Saturday each month 9:30AM -11:30AM – except July and August
CONTACT SCANCA, INC. FOR SPECIFICS – 202-271-5733

The SCANCA, INC. SUPPORT GROUP NEEDS LEADERSHIP
Let us know if you would like to assist in this effort.

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

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