



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 33

SUMMER 2018

Education Towards the Management of Sickle Cell

MESSAGE FROM THE EXECUTIVE DIRECTOR/PRESIDENT



Iola Y. Williams

Hello Friends:

Let us treasure the past, but don't let it blind us to our possibilities in the future. Let our past joys encourage us to venture out into unknown territory, to create new joys. As memorable as the past has been, now we have new treasures to create. SCANCA, INC. needs your support to continue what we and you together have obtained. Yes, twenty-four years is a wonderful milestone, however; we must do it together to reach toward another twenty-four years.

Friends, please consider coming to SCANCA, INC. workshops, social gatherings, and information sessions. When you are not there, we get the feeling that the sickle cell community has lost interest. Use our website often. We must do it together to reach toward another twenty-four years.

We can only continue with the combination of faith and assistance from the National Capital Area sickle cell community. SCANCA, INC. members want and appreciate your continual efforts and look forward to many hours with you.

God bless each of you!

Iola Y. Williams

SEPTEMBER IS NATIONAL SICKLE CELL MONTH

SCANCA, INC. 2018 BOARD OF DIRECTORS

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ANNUAL SPRING WORKSHOP

On Saturday, May 5, 2018, SCANCA, INC. held its Annual Spring Workshop, "Sickle Cell Disease and Mental Health: Its Not All in Your Head", led by Nigerian-born psychiatrist Akua Asare-Danso, M.D. Dr. Asare educated the group on the prevalence of mental illness in the general population, and why having a chronic disease can lead to issues in our mental health. These issues can then have physical consequences that are harmful to our physical health. We discussed strategies, which are listed in this newsletter, to keep our mental health in order. We also discussed the diagnosis and treatment of mental illness and the importance of early recognition of symptoms. Although mental illness can carry a stigma, we can't let that stop us from reaching out for help! Dr. Asare had a welcoming spirit and we were all encouraged by her presentation. We also enjoyed a nice lunch and wonderful conversation among those who were present. We hope to see you at our next event!

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SICKLE CELL DISEASE (SCD) AND MENTAL HEALTH -- "IT'S NOT ALL IN YOUR HEAD"

By Akua G. Asare-Danso MD

DEFINITIONS:

Tolerance – An effect in the body where the body needs more and more of a substance to get the same result. In the case of medication, the person uses more and more of the drug to get the same positive effects.

Withdrawal – Symptoms that occur after a person stops using a substance.

Dependence – When a person develops symptoms of tolerance and withdrawal if the substance is removed or stopped.

Addiction – When a person continues to use substances despite **negative** consequences of using or trying to get the substances. This happens because the substances have caused biochemical changes in the brain. The person has **uncontrollable cravings, can not stop using the drugs and uses the drugs continuously even though it causes harm to the person or others.**

COPING STRATEGIES

1. Awareness – It's important to understand Sickle Cell Disease (SCD). Learning about the illness, what it does to the body at a microscopic level, how it shows up, the symptoms and the treatment means that the person with SCD becomes his or her own advocate! Loved ones should also educate themselves about SCD. Everyone needs to understand it so that everyone can help. Listen to your body. You know best how your body responds to stress, illness, exercise, temperature changes and other situations. Think about triggers and make plans on how to deal with situations before crisis comes. For example, extremes in temperature can trigger crisis so taking that into consideration can help when planning vacations.
2. Communication – It can be hard to discuss the feelings of helplessness/hopelessness, loneliness, guilt (being a burden on the family /friends/loved ones), anger at having sickle cell, sadness, stigma and others, but constant, continuous, open, honest, respectful conversations are a key to dealing with the social isolation and other difficulties that come from having sickle cell. This will decrease miscommunications, decrease guilt, help persons with SCD access medical resources faster and help develop social support (see below).
3. Patience – SCD is unpredictable so learning to be patient with your body and how it responds to circumstances is important. For loved ones, remembering that the individual is dealing with an unpredictable, chronic illness means learning how to be accepting and tolerant of how the illness affects them. Sometimes the medical treatments or home remedies do not work every time. It is important to be open to changing up treatment options. It is important to be open to changes in plans.
4. Holistic Approach -- SCD is a chronic, unpredictable, sometimes debilitating illness so remember that everything is connected. How the person with SCD is thinking influences their emotions and their behaviors. How loved ones are thinking influence their emotions and behavior too. Addressing mental well-being is just as important as pain management. Having a healthy lifestyle keeps everyone going. Engaging in activities such as journaling and using art/dance to creatively express the emotions and experiences of having SCD or of being a loved one is helpful. Some people become active in advocacy, education and awareness programs to help others. They all work together.
5. Counseling – Persons with SCD sometimes need to seek professional counselors who can help them talk about, think through and work on their thoughts, emotions and behaviors. These are professionally trained individuals who are there to help others understand the reasons for what they think, say or do and how to best address and solve their issues. Loved ones also need professional counseling to discuss and solve particularly difficult issues that they may not feel ready or comfortable enough to discuss with others about SCD and how it affects them.
6. Social Support – No one wants to feel alone. No one wants to feel like a burden. Everybody wants to feel like they belong, are accepted and loved for who they are. We are social beings and we need one another to live. Persons with SCD should embrace their social supports and their loved ones should embrace them.. Persons with SCD need to know that they have people they can depend on and that they do not have to go it alone.
7. Proper Pain Management – The pain can be brutal, overwhelming and debilitating. It can be very hard to get the right pain medication every time but working with the primary care doctor or family physician can help with maintenance medications as well as when a crisis occurs. Going to the Emergency Room with loved ones who understand SCD and will push for immediate help because they know about the medications and this will help to decrease the difficulties that often arise including the stigmas of SCD.

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- 8. Healthy Lifestyle – Eat a diet with a wide variety of foods including fruits, vegetables, carbohydrates and proteins. Anemia is common so making sure to eat foods high in iron is helpful. Staying away from alcohol, fatty foods, pop/soda and junk foods will help the body’s immune system. Regular low-intensity exercise such as pilates, yoga and biking have all been known to help.
- 9. HOPE – SCD is not a death sentence!! It is a chronic illness that can be managed so that the person lives a fruitful, fulfilling life.

Members and Friends in the Study mode at the Workshop



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TRIVIA

OLD TESTAMENT BOOKS WORD SEARCH GAME

If you have a Book called “The Bible” try this search game. It has 27 answers.

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

IMPORTANT INFORMATION FOR YOU!!

QUALIFYING FOR SOCIAL SECURITY DISABILITY WITH SICKLE CELL DISEASE

By: Eric Minghe

If you or your child has sickle cell anemia, you may be eligible for financial assistance. The [Social Security Administration \(SSA\)](#) offers aid to people and adults of all ages who are unable to work or participate in typical childhood activities. Sickle cell disease is listed as a qualifying condition, meaning you could be eligible for monthly payments for your medical bills, paid medication, childcare, rent, travel expenses, and any other daily living needs.

Medically Qualifying for Benefits

The SSA uses its own medical guide of qualifying criteria, known colloquially as the [Blue Book](#), to evaluate disability applicants and award benefits to those who qualify. Sickle cell disease is listed under [Section 7.05](#) of the Blue Book. Under this listing, there are four ways to qualify.

1. You have documentation proving you have severe pain from sickle cell disease requiring narcotic medication at least six times within any year, with at least 30 days between crises.
2. You have complications of hemolytic anemia requiring three hospitalizations within one year, each at least 30 days apart. A stay in the hospital must last at least 48 hours to count.
3. Your hemoglobin measurements are 7.0 grams per deciliter or less. You will need three measurements within a yearlong period to qualify.
4. You have beta thalassemia major, which requires lifelong RBC transfusions at least once every six weeks.

The Blue Book was written for medical professionals, and you may not immediately know if you qualify with sickle cell disease. Because the entire Blue Book is [available online](#), you can review [Section 7.05](#) with your hematologist to determine if you qualify for benefits.

Children and Disability Benefits

Qualifying criteria for children with sickle cell disease is less strict than for adults, but children on disability benefits will have strict income limitations. Anyone under age 18 is only eligible for [Supplemental Security Income](#), or SSI benefits. These are only awarded to the most financially needy Americans. If you are applying on behalf of a minor child with sickle cell disease, your child's claim could be denied if your household income is too high. The larger your family, the higher your income limit will be.

For example, a single parent with one child could only earn \$38,000 per year and still qualify. A two parent family of five could earn more than \$55,000 and still qualify for SSI benefits. Review the SSA's online chart to determine how much income your family could earn while still qualifying.

Unfortunately, financial eligibility is the top reason why children are [denied benefits](#) with sickle cell disease. The good news is once your child turns 18, your income no longer counts towards his/her SSI limits even if your child still remains in the home.

Starting your Application

The [easiest way to apply](#) for Social Security disability benefits is online from the comfort of your own home. If you are applying on behalf of a child, or if you would rather have assistance applying, you can do so in person at [your local SSA office](#). Call the SSA toll free at 1-800-772-1213 to schedule an appointment to apply today. It usually takes three to five months to hear back from the SSA. Once approved, you can focus on what is important: your health.

Resources Found Via:

<https://www.ssa.gov/>

<https://www.disability;out-benefits-help.org/glossary/social-security-blue-book>

<https://www.ssa.gov/disability/professionals/bluebook/7.00-HemicandLymphatic-Adult.htm#7.05>

<https://www.ssa.gov/disability/professionals/bluebook/>

<https://www.ssa.gov/benefits/ssi/>

<https://wwwdisability-benefits-help.org/content/denied-social-security>

<https://www.ssa.gov/applyfordisability/>

<https://secure.ssa.gov/ICON/main.jsp>

Sickle Cell Trait May Not Contribute to Stroke Risk -Genetic variant not an independent predictor among African Americans <https://www.medpagetoday.com/neurology/strokes/72488>

Sickle cell trait may not be an independent genetic risk factor for ischemic stroke among African Americans, a new meta-analysis suggests.

In a review of four studies with more than 19,000 African-American participants, Hyacinth I. Hyacinth, MD, PhD, MPH, of Emory University School of Medicine in Atlanta, and colleagues reported no association between heterozygosity for the sickle cell mutation or sickle cell trait and incidence of ischemic stroke in [JAMA Neurology](#).

"Sickle cell trait was not associated with a higher risk of ischemic stroke among African Americans," Hyacinth told *MedPage Today*. "This negative study and its findings are important as we attempt to develop more targeted approaches for stroke prevention."

**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, D. C. 20018-0879

OR

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

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SCANCA, INC. IS NO LONGER ASSOCIATED WITH CFC

SEPTEMBER IS NATIONAL SICKLE CELL MONTH

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**TAKING CHARGE OF YOUR MENTAL HEALTH
STRATEGIES TO KEEP OUR MENTAL HEALTH IN ORDER**

FIND THE RIGHT SPECIALIST



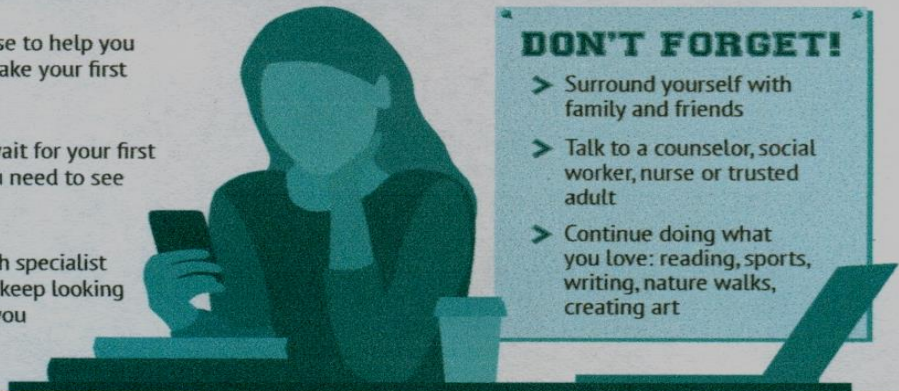
Ask your doctor or nurse to help you find a specialist and make your first appointment



There may be a long wait for your first visit, so speak up if you need to see someone right away



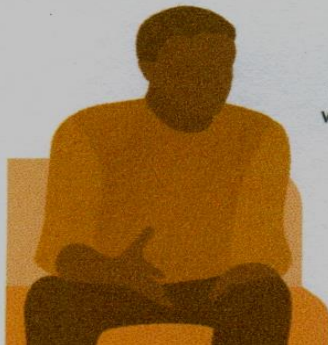
If the first mental health specialist you see isn't a good fit, keep looking for one who works for you



DON'T FORGET!

- > Surround yourself with family and friends
- > Talk to a counselor, social worker, nurse or trusted adult
- > Continue doing what you love: reading, sports, writing, nature walks, creating art

MAKE YOUR FIRST APPOINTMENT COUNT



Be ready to talk about your health history and what you're experiencing



Be clear about what you want and need to get better



You may be asked to fill out a questionnaire describing your mental health experience




Ask the mental health specialist to explain treatment options so you understand the plan and what you need to do

NAVIGATING YOUR INSURANCE

- 📍 Involve someone with experience to help you
- 📍 Call your insurance company to ask what mental health benefits are covered
- 📍 To find a provider, visit your insurer's website or call the number on your insurance card


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Workshop continues from page 6

ASK QUESTIONS



If I have thoughts that scare me what should I do?


How often should we meet? What can I do between appointments if I need help?




Do I have to take medication? What does it help with? What are the side effects?

How long will it take for me to feel better, a few days, weeks or months?


STAY INVOLVED




Keep a wellness log and monitor your progress



Ask for changes if your treatment plan is not working for you



Stick with it; most therapies and medications take time to work



Your treatment plan may change, so be an active partner in this process

LIVE WELL


- Remember that you have control over living well
- Find a routine that works for you that includes a healthy diet, exercise and regular sleep patterns
- Stay close to your support network. Engage family, friends, teammates and your faith community. Think about joining an online community
- Be realistic and mindful of your needs and know your limits

GETTING THROUGH IT

- Try staying away from drugs and alcohol. This is not always easy, so find strategies that work. Using drugs or alcohol to feel better is harmful to you.
- If you use alcohol or drugs, be honest and tell your therapist or doctor because it affects your care plan.
- Stay positive. Surround yourself with positive messages, people and activities. This will help you to feel better.

Follow Us!

NAMI NAMIconnunicate NAMIconnunicate www.nami.org



NAMI
National Alliance on Mental Illness

Answers to WORD SEARCH GAME page 3

Genesis – Exodus – Leviticus – Numbers – Deuteronomy – Joshua – Judges – Samuel – Kings – Chronicles – Ezra – Nehemiah – Esther – Job – Psalms – Proverbs – Isaiah – Jeremiah – Ezekiel – Daniel – Hosea – Joel – Amos – Jonah – Micah – Habakkuk – Haggai

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

SCANCA, INC. ANNUAL CHRISTMAS PARTY

EARLY December 2018 - 12n – 2pm
8400 Corporate Drive - Landover, Md. 20785
first floor meeting room

RESERVATIONS NEEDED – rsvp@scancainc.org
CHECK SCANCA, INC.'s WEBSITE FOR UPDATES!!

202-271- 5733 for information

STOMP OUT SICKLE CELL MOVE-ON EVENT

September 8, 2018 - Howard University Hospital
For more Information: www.sicklecell.howard.edu

**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.

SCANCA, INC. INDIVIDUAL AND FAMILY COUNSELING

Available by appointment only.
Call SCANCA, INC. at 202-271-5733



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