THE NBNA NEWS IS THE OFFICIAL PUBLICATION OF THE NATIONAL BLACK NURSES ASSOCIATION

NATIONAL BLACK NURSES ASSOCIATION

NBNA NEWS

SPECIAL EDITION ON SICKLE CELL DISEASE

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Sickle Blood Cells

NBNA NEWS

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A Message from the Co-Editor-in-Chief

Pandemic Nursing and Self-care

Jennifer J. Coleman, PhD, RN, CNE, COI
Co-Editor-in-Chief

The coronavirus 2019 (COVID-19) continues to evolve, and many of our communities are in various stages of lockdown. In our ongoing efforts to mitigate the spread of the virus, we continue to implement protective measures against the novel threat. Across the U.S. we see data that report numbers of infections, increasing numbers of persons who have been exposed, and the numbers of deaths related to COVID-19.

The stress of living during a pandemic is evident when we see fear on the faces of parents who must decide whether or not to send their children back to school, when we see sadness on the faces of relatives who are unable to visit their loved ones in long-term care facilities, when we see despair on the faces of those who are evicted from their homes because they have lost their jobs and are unable to pay their rent, and when we see the faces of families who have lost multiple family members to COVID-19. The continuing changes and seemingly never-ending effects of the virus are huge contributors to feelings of panic and loss of control.

During the COVID-19 pandemic, nurses are at increased risk based on the nature of nursing work. While the vulnerability of nurses includes the usual risk factors, nurses carry the additional responsibility of being on the frontlines caring for patients who are affected with COVID-19. Persons who seek assistance at health care facilities may be asymptomatic carriers of COVID-19, may be exhibiting symptoms, or their status may be unknown. Thus, nurses have expressed very real fears of contracting the disease and of infecting family members upon returning home at the end of a work day. Long shifts and fears of limited personal protective equipment are also the reality of nurses in the clinical areas. Many nurses in the clinical area have served as surrogate family for critically ill and dying patients whose family members were not allowed to visit. Further, the need to limit physical contact with others also limits the opportunities for nurses to receive emotional support from colleagues. I have always considered nursing to be a team sport where we work closely together, collaborating with each other, to provide the best possible care of our patients. Currently, however, we must keep our distance whenever possible, and informal "just-in-time" communications have been minimized. The lack of the usual unscheduled contacts with colleagues may result in the lack of needed peer emotional support during these stressful times.

I encourage nurses not to neglect self-care at a time like this. Pay attention to your physical and emotional health. Eat nutritious snacks and meals, get enough sleep, and try to engage in physical activity daily. Remember to stay hydrated with water, and avoid excessive caffeine and sugary drinks. Mental health support is needed during stressful times. Unfortunately, we may be reluctant to seek mental health assistance because of the perceived notion that the actual contact with a mental health professional means there is some type of defect in a person. Far from it – mental health support can actually strengthen a person's emotional bank.

A Message from the Co-Editor-in-Chief

Plan to visit NBNA's affirmations, webinars, and podcasts available on our NBNA website. Plan also to pay attention to your colleagues. If a nurse friend seems overwhelmed, uncertain, fearful, or anxious, reach out to them. Encourage them to take a break; offer to help with patient care; write a note of encouragement. Think about stress-reducing strategies that might help you and your colleagues strengthen your banks of emotional wellness.

As nurses, we are committed to the care and well-being of others. Let us remember to pay attention to our personal health and well-being as well as that of our colleagues.

Respectfully,

Jennifer J. Coleman, PhD, RN, CNE, COI
Co-Editor-in-Chief

NBNA Presidential Moments

In this issue of *NBNA News*, we continue our look at the NBNA past presidents. Each of our past leaders has left an imprint on the organization and has been responsible for ensuring the actualization of NBNA's original mission: to serve as the voice for Black nurses and diverse populations ensuring equal access to professional development, promoting educational opportunities, and improving health.

5th NBNA President – C. Alicia Georges, EdD, RN, FAAN (1987-1991)

Dr. C. Alicia Georges earned her undergraduate nursing degree at Seton Hall University College of Nursing and her M.A. in Community Health Nursing Administration and Supervision from New York University. She received her EdD in Educational Leadership and Policy Studies at the University of Vermont. Dr. Georges is currently professor and chair of the department of nursing at Lehman College, City University of New York. Among her numerous honors and awards, she is a Fellow of the American Academy of Nursing, Fellow of the New York Academy of Medicine, and National Volunteer President of the AARP Board of Directors. She has served on the National Advisory Council on Nursing Education and Practice. In 2019 Dr. Georges was inducted as a Living Legend in the American Academy of Nursing. She has received the American Nurses Association Mary Mahoney Award for her efforts to increase minority representation in nursing.

Dr. Georges has spoken on nursing and health care issues throughout the United States, Africa, South America, Europe, and the Caribbean and is well known for her work and expertise in cultural diversity. She continues an integral relationship with the Center to Champion Nursing in America, *the Future of Nursing: Campaign for Action*.

Dr. Georges is co-founder and president of the National Black Nurses Association Foundation. As the 5th NBNA president, Dr. Georges launched the National Black Nurses Day on Capitol Hill in 1988. This annual event is dedicated to educate the U. S. Congress on health care disparities and policy issues as Black nurses from across the nation come to Washington, DC. to advocate for nursing and minority health.

6th NBNA President – Linda Burnes Bolton, Dr. PH, RN, FAAN (1991-1996)

Dr. Linda Burnes Bolton began her career in nursing by earning a Bachelor of Science in Nursing from Arizona State University. She received master's degrees in nursing and in public health and a doctorate in public health from the University of California, Los Angeles. She holds an honorary doctor of science degree from State University of New York. Dr. Bolton is currently Vice President for Nursing, Chief Nursing Officer, and Director of Nursing Research at Cedars-Sinai Medical Center. During Dr. Bolton's tenure, Cedars Sinai has achieved Magnet designation from the American Nurses Credentialing Centers five times in a row for a total of 20 consecutive years. Dr. Bolton has served as president of the American Academy of Nursing, the American Organization of Nurse Executives, and the National Black Nurses Association. In 2016 Dr. Bolton was named a Living Legend by the American Academy of Nursing. She has received Lifetime Achievement awards from NBNA and the American Organization of Nurse Executives. Dr. Bolton's expertise in diversity, workforce issues, education, and equity is recognized and valued worldwide.

Under Dr. Bolton's leadership as NBNA's 6th president, the NBNA Foundation's first fund raiser was held and honored Congressman Louis Stokes and Congresswoman Eddie Bernice Johnson, the first Black nurse elected to congress. During Dr. Bolton's presidency, NBNA's active involvement in health care reform debate included the call for (a) basic standard benefits for all, (b) consumer participation, (c) and incentives for health care providers to practice in underserved areas. Development of NBNA's strategic plan for the 21st century detailed membership growth, community health education and disease prevention, and sustained public policy campaigns.

Population Health Committee: Sickle Cell Disease –A Call to Action

Martha A. Dawson, DNP, RN, FACHE
President, National Black Nurses Association

After my installation as the 13th President of the National Black Nurses Association (NBNA) on July 28, 2019, I started my journey to represent NBNA members, and find the best in all of us. My first official presidential visit was with the First Coast Black Nurses Association Scholarship Brunch in Jacksonville, FL at the University of North Florida. I spent three days meeting and networking with the chapter. First, I participated in a recruitment video, and the next day I visited an older adult community center where our members were participating in a funded community research project. I was the keynote speaker for their scholarship brunch. However, the highlight of my visit was the interprofessional and community education workshop on sickle cell disease (SCD) sponsored by Novartis. There were two keynote speakers: a Black pediatrician and researcher from Johns Hopkins University and a mother who had lost her young son to sickle cell disease. This mother has written a child-centered educational book in her son's memory. Many of our chapters are collaborating with community partners to address SCD. My local chapter, the Birmingham Black Nurses Association, annually participates in the SCD space. However, the presentations at the scholarship brunch in Jacksonville inspired and encouraged me that there is more that NBNA needs to do.

Leaders must listen and seek opportunities to influence and support "good work" among those they serve. Dr. Katherine Tucker, immediate past board member, approached me during our 2020 NBNA Day on Capitol Hill about the need for NBNA to help define and navigate the growing space of "population health." Therefore, we discussed establishing the NBNA Population Health Committee. This was another seed that was planted, and it enabled me to reflect about how this could intersect to a SCD platform. While I was thinking about how to merge these two interests, I received a call from Dr. Nadine Matthie, an NBNA member and nurse scientist at Emory University, who shared her research and interest in SCD. By the end of conversation, the vision of how to move forward became very clear.

Then, I received an invitation from Lisa Davis, President, Midlands of South Carolina BNA to attend their first scholarship and education event that also addressed SCD. Wow! The highlight of the event was a patient and community panel; this chapter's event was also sponsored by Novartis. The two patient representatives highlighted what I had identified and was learning: Persons with SCD are living longer, and primary care adult providers and adult emergency room staff have little knowledge about SCD and how to treat and engage with this patient population. During my visit, I was able to network with so many NBNA members who work at the University of South Carolina College of Nursing. I met five or six faculty members with a research focus in SCD, public health, and diversity.

By mid-March, COVID-19 was taking over our world and daily focus. I had a conversation with Dr. Cyntheia Bethel-Jaiteh, a pediatric nurse practitioner. She voiced concerns about a lack of focus on the pediatric patient population within NBNA. After this conversation, the NBNA Population Health Committee was established with the initial focus on SCD and pediatric patients, a perfect combination of nurse leaders and scientists to address a health issue that involves population health across the life span. In addition, Dr. Millicent Gorham and I are in conversation about SCD and the need for NBNA to have a larger presence in this space because of the impact it has on the Black/African American population.

Letter From the President

Sickle Cell Disease is a complex health problem that disproportionately affects Blacks/African American, Hispanics, and Native Americans. According to the Sickle Cell Disease Foundation, 250 million people have SCD, making it the most common genetic disease worldwide. In the US, there are 90,000 people living with SCD. About 1 in 500 Black births are children with SCD or SC trait. SCD is a hemoglobin disease, and each year about 300,000 children are born with a major hemoglobin disease worldwide. This issue of NBNA News is focusing on SCD and the early work of our Population Health Committee. I would like to thank the nurses, leaders, providers, translational and research scientists, and corporate partners for coming together to address this important health issue. A special thank you to Dr. Carol Jenkins-Neil, Dr. Frances E. Ashe-Goins, Dr. Keneshia Bryant; Dr. Nadine Matthie, Dr. Coretta Jenerette and Dr. Cheedy JaJa (Sickle Cell Disease Co-leads); and, Dr. Cyntheia Bethel-Jaiteh and Dr. Pamela Bryant (Pediatric Co-leads). I invite you to learn and share information from these articles in your communities and classrooms. Thank you for all that you are doing to help our communities. NBNA members - You are the BEST.

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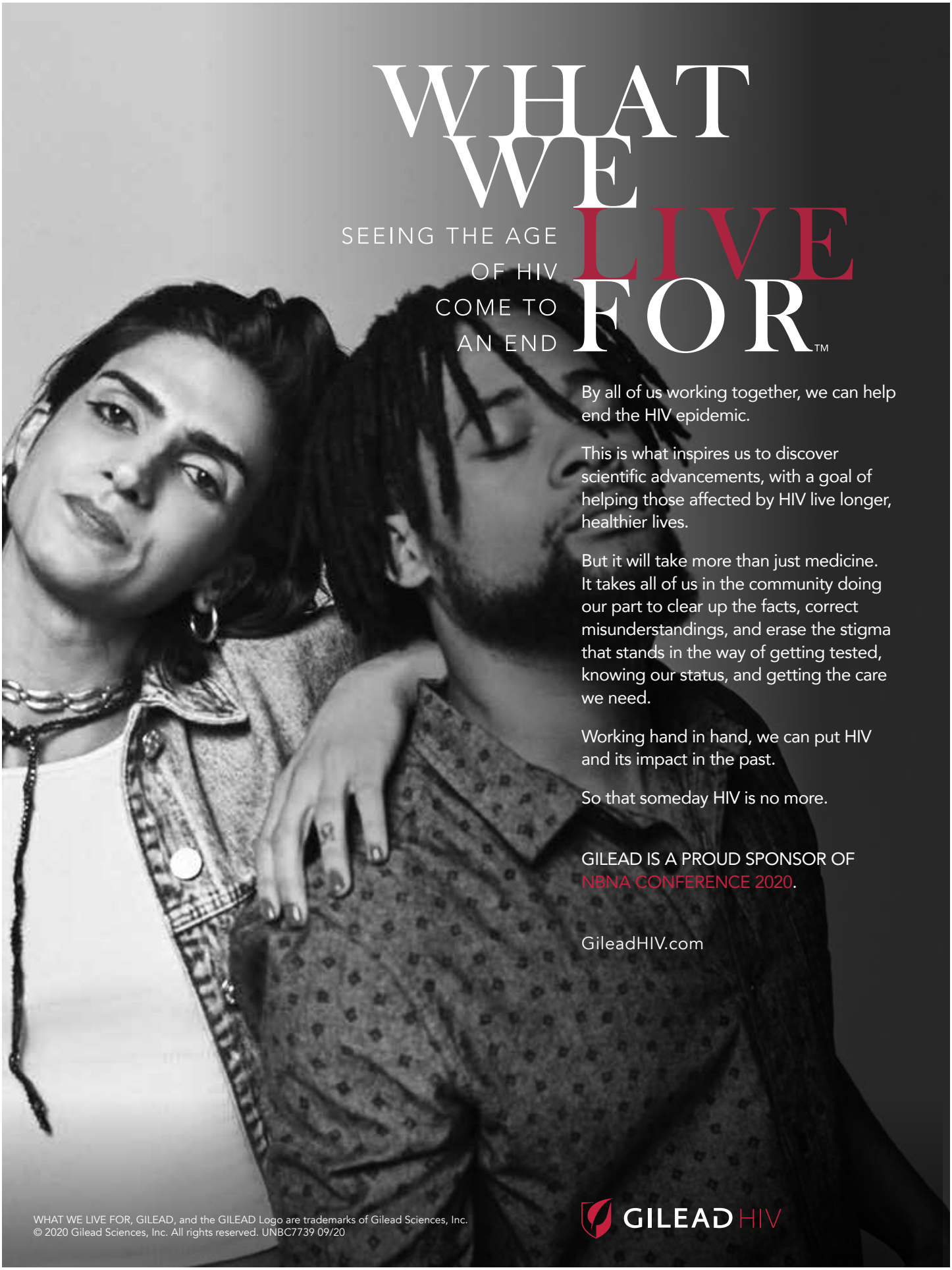
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Sickle Cell Disease in 2020: Awareness and Advocacy

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Introduction

It has been over a century since sickle cell disease (SCD) was first described by Dr. James Herrick and almost 15 years since SCD was recognized as a global health problem by the World Health Organization. September 2020 is National Sickle Cell Awareness Month and a time to evaluate progress in the United States (U.S.) and globally. Moreover, it is a time for nurses to reprise their role in raising awareness of SCD and begin marshaling resources to improve outcomes for people living with SCD worldwide. To date, early detection, interventions in infancy, medical advances, and specialized multidisciplinary management in the U.S. and Europe have progressively transformed SCD into a chronic condition with longer life expectancy and higher quality of life. However, progress has been uneven elsewhere.

State of Care

During the past six years in the U.S., clinical guidelines and federal regulations have enabled healthcare professionals to improve the quality of care provided to SCD patients. Many SCD research studies are being conducted, and different treatment options are available. In the last two years, the FDA has approved three new SCD medications, and other medications are in development. Ongoing innovative research promises to shift current treatment options from supportive care to curative therapy.[1] These ongoing scientific advancements, coupled with education and self-management, have contributed to the transformation of SCD into a chronic health condition. But with chronic conditions, there are associated physical and psychosocial challenges.[2] Despite the advances, there is a lot more work to be done as health disparities and inequities continue to dominate the lived experience of individuals with SCD. In rural areas, access to specialty care remains inadequate. In urban areas, some adolescents and adults who require frequent emergency room visits for pain are often labeled as “drug seekers” or “addicts”. This label often leads to withholding of adequate opioid-based pain therapy. In the context of general disparities in pain management, SCD patients represent an even more vulnerable and underserved segment of the minority population who suffer from additional disparities and discrimination. The socio-economic status of patients with SCD and the nature of the disease subject them to further healthcare disparity.[3]

In several lower- and middle-income countries in Africa, South America, and the Caribbean, inadequate care infrastructure and poor SCD outcomes are common. In the U.S. and Europe, the public-health strategy of newborn screening, preventive care, and active clinical management of SCD has resulted in improved survival rates for children with SCD. In contrast, the vast majority of Africa’s children with SCD are not diagnosed before the second year of life or even later. If they die undiagnosed with SCD, death is often attributed to anemic, vascular, or infectious complications. A significant barrier to implementation of timely preventive measures in African countries has been the absence of early diagnosis through laboratory-based newborn screening programs.[4] Recently, the development and validation of new point-of-care tests for SCD addresses many of the structural and cost barriers to these programs in Africa.[5] However, there is an urgent need for linkage to comprehensive care, including parental education to address high SCD infant mortality rates and ensuring that children born in Africa have access to the standard, public healthcare package for SCD children that has been used in both middle- and high-income countries over the past 50–60 years.[6]

The Role of Nurses in Sickle Cell Disease Management

In 2020, the Year of the Nurse and the Midwife, nurses can do the following to help individuals with SCD:

1. **Obtain professional education to develop expertise in SCD**
   In the U.S., nurses should become knowledgeable about clinical and research development in SCD. They can do so by taking advantage of recent programs in the resource list, that are aimed at training health care providers in SCD.

2. **Use new guidelines in clinical practice**
   Nurses should use guidelines to educate themselves,

Dr. Nadine S. Matthie is an Assistant Professor in the School of Nursing at Emory University in Atlanta, Georgia. Her research focuses on pain and self-management in young adults living with sickle cell disease, and she is currently working on developing non-pharmacological, home-based, pain self-management strategies for their chronic pain. Dr. Matthie's most recent article, titled Prevalence and predictors of chronic pain intensity and disability among adults with sickle cell disease, was published in the January-June 2020 issue of Health Psychology Open.

Dr. Coretta M. Jenerette is a Professor and the Associate Dean for Diversity, Equity, and Inclusivity in the College of Nursing at the University of South Carolina. Her research focuses on improving health outcomes for individuals and families living with sickle cell disease. Dr. Jenerette was recently named Sickle Cell 101's National Sickle Cell Advocate of the Year.

Dr. Cheedy T. Jaja is an Associate Professor in the College of Nursing at the University of South Carolina in Columbia, South Carolina. He is an international expert in sickle cell disease pharmacogenetics. In his pioneering research, he has made significant discoveries that are published in prestigious interdisciplinary and nursing journals, which are likely to make a significant difference in the way sickle cell disease is treated.

along with family members and caregivers of individuals with SCD; thereby, raising awareness and addressing the needs of patients.

3. **Be a nurse champion for SCD in the U.S. and Africa**
   Nurse champions for SCD should have appropriate competency-based training and context-specific education to provide SCD services to adults and children effectively. These services include management of pain and disease complications with low-cost, established, evidence-based standard of care.

Nurses can prepare today's SCD affected individuals to benefit from tomorrow's curative solutions as they become available.

Resources

1. National Heart, Lung, and Blood Institute clinical guidelines – Evidence-Based Management of Sickle Cell Disease: Expert Panel Report, 2014 https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease
2. American Society of Hematology – 2020 Guidelines for sickle cell disease: Management of acute and chronic pain https://www.hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/scd-guidelines-management-of-acute-and-chronic-pain
3. The Sickle Cell Disease (SCD) Training and Mentoring Program (STAMP) https://www.minorityhealth.hhs.gov/sicklecell/index.html
4. Johns Hopkins Sickle Cell Disease Project ECHO (Extension for Community Health Outcomes) https://www.hopkinsmedicine.org/Medicine/sickle/providers/
5. Sickle Cell Disease Association of America Community Health Worker Training Program https://www.sicklecelldisease.org/our-initiatives/community-health-worker-training/
6. International Association of Sickle Cell Nurses and Professional Associates https://www.iascnapa.org/
7. Sickle Cell Community Consortium https://sicklecellconsortium.org/

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Sickle Cell Disease and Health Equity: What's the Nurse's Role?

Shammara N. Pope, MPH
Mary M. Hulihan, DrPH

Consider what happens when poor health outcomes associated with a chronic disease are not just the result of the biological impacts of that condition on the body, but also the combined effect of an under-resourced healthcare system, lack of training about that condition in the medical education system, and systemic racism. These challenges are a reality that many individuals in the United States with sickle cell disease (SCD) face as they navigate the complexities of living with a lifelong condition. SCD, which mostly affects people of color, often requires frequent trips to the hospital and large amounts of pain medicine, and there are relatively few healthcare providers who have clinical expertise and experience to manage the complications of SCD. This article focuses on the latter topic—healthcare providers' knowledge of SCD—and the potential opportunities for nursing professionals to help those with SCD live healthier and longer lives.

One of the biggest disparities experienced by the SCD community is the lack of access to specialized care and providers who understand SCD, a condition that is present from birth and affects every organ and system of the body for a lifetime. Most healthcare curricula, whether for nurses, advanced practice providers, pharmacists, or physicians provide little or no education on SCD. As a result, there are few providers, especially in adult care, with the type of knowledge and training needed to address the complexity of this disease (Haywood, 2009). Patients with SCD often rely on primary care or emergency department providers without SCD expertise to manage their disease, which can result in delayed diagnoses of, or inappropriate management of, SCD complications. The lack of access to specialized care also may have many unintended consequences beyond the direct impacts on a person's medical care. People with SCD encounter inappropriate suspicions about the legitimacy of their intense pain episodes and their need for appropriate treatment, including opioid medications, especially when receiving care in the emergency department (Singh, 2016); this is often compounded by long waiting room times, with potentially life-threatening results. For the roughly 60%–70% of individuals with SCD who are Medicaid beneficiaries, care can be especially difficult to access, as many medical offices are unwilling to accept new patients with this form of insurance (NCHS, 2015).

As difficult and overwhelming as these intertwined issues may be, there are areas where healthcare providers, nurses in particular, can play an important role to improve health and health outcomes, two important components of health equity. Nurses are often the first and last point of care in the medical setting and have the most frequent contact with patients in hospitals. One of the most basic and fundamental ways to be a nurse champion for people with SCD is to learn more about its complications and treatments and the specific roles that nurses play in this care (Tanabe, 2019). There are a number of professional organizations, community-based organizations, and state and federal agencies with publicly available educational resources on SCD for healthcare professionals and patients (www.hematology.org; https://www.nhlbi.nih.gov/sites/default/files/media/docs/sickle-cell-disease-report%20020816_0.pdf; https://www.cdc.gov/ncbddd/sicklecell/hcp.html). Second is a willingness to listen and involve patients in decision-making about their health care. People with SCD have a lifetime of experience with this disease, how it manifests, what medical and non-medical strategies work best to relieve their pain, and when a complication is a "normal" part of their SCD experience and when it is not. And, finally, nurses can serve as champions for the sickle cell community within their professional networks. Being an SCD advocate away from the bedside, such as during care team meetings and administrative discussions, allows for additional opportunities for people with SCD to be "seen" and to have their needs truly acknowledged and met.

Health equity is achieved when everyone has the opportunity to be as healthy as possible (www.cdc.gov/healthequity/index.html). Addressing health disparities, which are preventable differences in the burden of disease, can help measure progress toward achieving true health equity (Braveman, 2014). Working together as a team is important to help identify when a healthcare visit or encounter may be related to SCD or one of the many associated complications. Conversely, it is just as essential to recognize that a person with SCD may be at risk for other health issues and chronic diseases, and so not all health issues should be attributed to their

Shammara Pope is the Associate Director for Policy. They have both been working with the Division's sickle cell disease program for 9+ years. Shammara focuses on public health policy and partnership development.

Mary Hulihan is a Health Scientist for the Division of Blood Disorders, National Center on Birth Defects and Disabilities, Centers for Disease Control and Prevention (CDC). They have both been working with the Division's sickle cell disease program for 9+ years. Mary works with partners throughout the United States to build surveillance systems and develop and disseminate health education materials.

SCD. Taking these steps will not resolve every challenge faced by individuals with SCD, but they may help lay the foundation of a path to health equity.

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The International Association of Sickle Cell Nurses and Professional Associates (IASCNAPA)

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IASCNAPA provides a platform for nurses, nurse practitioners, physician assistants, social workers, sickle cell advocates, and other healthcare professionals caring for individuals with sickle cell disease (SCD) to improve the care of people with sickle cell disease through advocacy, standardized practice, and education. The organization was founded in 1990 and is celebrating its 30th anniversary this year.

IASCNAPA is a United States-based, international non-profit, tax exempt organization of nurses and other professional associates who volunteer their time to maintain high standards in the provision of quality and accessible health care and support for individuals with SCD. IASCNAPA members raise awareness about SCD in community and health care settings and provide support in the form of scholarships for post-secondary education to people with SCD to help encourage continued growth and education.

Sickle Cell Disease (SCD) is an inherited, complex and lifelong medical condition that affects more than 100,000 people in the United States is characterized by red blood cells (RBCs) that become hard, rigid and sickle-shaped, and sticky. These RBC changes lead to decreased oxygen to the body, inflammation, and intense pain and other serious conditions such as infections, anemia, tissue damage, stroke, organ failure, and even death. SCD complications may impact physical and social well-being.

In the United States, most people with SCD are African Americans, however people of any race or ethnicity can have SCD.

People who have SCD often suffer complications that make life extremely challenging. The most common complication is pain. Pain and other illnesses can lead to frequent emergency department visits, long hospital stays, and unplanned illnesses that impact quality of life and often limits education and employment opportunities for people with SCD.

IASCNAPA members actively work to improve the lives of people with SCD. Goals and objectives of the organization are listed below:

- To provide an organizational platform for IASCNAPA members throughout the world in order to improve care of people with sickle cell disease.
- To establish guidelines for standards of nursing care for people with sickle cell disease.
- To participate in collaborative partnerships to improve care for people with sickle cell disease through advocacy, education, and awareness.
- To advocate and support legislation that improves treatment, research, awareness, and advocacy of people with sickle cell disease.
- To serve as an educational platform to provide sickle cell education to IASCNAPA members.
- To provide educational opportunities for people with sickle cell disease through the IASCNAPA scholarship fund.

IASCNAPA collaborations and activities include symposiums, workshops, presentations, and material development for healthcare providers and people with SCD. Recent IASCNAPA activities are listed below:

- Award of four $1,000 scholarships for post-secondary education to people with SCD
- Expert Panel Endorsement for the Evidence-Based Management of Sickle Cell Disease released by the National Institutes of Health

- Member of the American Society of Hematology Sickle Cell Disease Coalition (SCDC) which is composed of public health, research, and provider organizations, patient groups, faith-based organizations, federal agencies, industry representatives, and foundations with an interest in *SCD.*
- Sickle Cell Disease Association of America (SCDAA) in Baltimore, MD collaborations for nursing and patient education sessions.
- National Sickle Cell Community Consortium (SCCC) collaboration to educate providers and people with SCD. The SCCC is the largest organization founded by people with SCD for people with SCD.
- Nursing educational sessions at Foundation for Sickle Cell Disease Research national symposium.
- Participant: Sickle Cell Disease National "Day on the Hill" in Washington, DC
- Participant: Federal Partners Listening Session for Sickle Cell
- Collaboration with Pi Chapter of Chi Eta Phi Sorority, Inc. to host annual Skill-Building Workshop for Adolescents and Young Adults with Sickle Cell Disease

For more information, please visit IASCNAPA below:

IASCNAPA Website: www.iascnapa.org

On Twitter: @iascnapa

On Facebook: International Association of Sickle Cell Nurses and Professional Associates

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Sickle Cell Disease – Patient Burden Persists, Yet Hope Comes into View on the Horizon

Tammy Boyd, JD, MPH

Tammy Boyd, Chief Policy Officer & Counsel, Black Women's Health Imperative

Sickle cell disease (SCD) – an inherited genetic form of anemia arising from problems with the structure and function of red blood cells – has a dramatic impact on the lives of those living with it.

The most common inherited blood disorder in the U.S., SCD affects about 100,000 Americans. It has a disproportionate impact on African-Americans – in fact, about 1 out of every 13 Black or African-American babies is born with the sickle cell trait, and SCD occurs in roughly 1 in every 365 Black or African American births. (CDC)

SCD results in a shorter lifespan – an average 30-year reduction – and a tremendous impact on an individual's body, including severe anemia, blockage of blood vessels that causes severe and unpredictable pain and long-term blood vessel dysfunction (called vasculopathy). These health issues lead to additional serious medical problems such as acute chest syndrome, organ failure that can lead to sudden death, stroke and cognitive impairments that can impact "intellectual functioning, language and verbal abilities, visual-motor and visual-spatial processing, memory, sustained attention, executive functions, and academic achievement. (https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1094&context=psych_diss)

Beyond its effect on health, the impact SCD and its associated symptoms and outcomes have on the lives of those living with it and their families cannot be over-stated:

- Psychological maladjustment – such as "emotional and behavioral problems, poor self-concept and interpersonal functioning, limited athletic abilities (due in part to illness restrictions), and poor academic performance" – persist across the lives of children and adolescents living with SCD. (https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1094&context=psych_diss)
- Children living with SCD commonly experience mental health issues that can directly and indirectly affect "pain perception, functional impairment, and other patient-reported health outcomes." (https://ashpublications.org/blood/article/134/Supplement_1/4687/428741/Mental-Health-Screening-in-a-Pediatric-Sickle-Cell)
- Children and adolescents living with SCD and their caregivers must frequently deal with missed school and work, and experience increased stress due to this, because of the unpredictability of pain events associated with SCD and as disease care demands increase. (https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1094&context=psych_diss)
- SCD can also have a dramatic impact on the financial situation for individuals living with the disease and their families. Vaso-occlusive and chronic pain crises can lead to substantial economic loss and disability; hospitalizations, blood transfusions, frequent visits to specialists and medications for pain and other symptoms can add directly to these economic losses, and loss of employment, resulting from living with SCD or caring for someone living with the disease results exponential losses. (https://emedicine.medscape.com/article/205926-overview#a7)

New Treatments Currently on the Scene and on the Horizon

A vast paucity of treatments historically existed for people living with SCD – however this dearth is changing and could be on the verge of a revolution. For two decades, clinicians had just one

drug – hydroxyurea – to treat the relentless disease. Three new drugs have been approved since 2017 (https://www.mdedge.com/hematology-oncology/article/219361/anemia/new-sickle-cell-drugs-give-hope-access-remains-barrier): The amino acid L-glutamine (Endari), Crizanlizumab-tmca (Adakveo) and Voxelotor (Oxbryta).

Each of these new treatments can be used as monotherapy and can provide additional pain- and hospitalization-reduction and anemia-improving benefits when used concomitantly with hydroxyurea. They are also welcome options for patients for whom hydroxyurea therapy is inappropriate.

The new treatments that have come to market could be just the beginning. According to a report published in 2019, 17 new treatments are being developed specifically for SCD. These treatments are in various stages of clinical trial development and FDA approval.

The multitude of treatments in development represent new uses of established medicines and cutting-edge approaches "such as RNA interference, gene-edited stem cell therapy and gene therapy."

(https://catalyst.phrma.org/new-report-shows-17-innovative-medicines-in-development-for-sickle-cell-disease)

If approved, these treatments have the potential to change the course of the disease – and the lives of – for people living with it through approaches such as: replacing "the function of a faulty gene with a healthier copy; [inactivating or "silencing"] a gene to interrupt a disease process, [and introducing] a new or modified gene into certain cells to help treat a disease." (https://catalyst.phrma.org/new-report-shows-17-innovative-medicines-in-development-for-sickle-cell-disease)

Barriers to Better Treatment

Despite these exciting advancements in SCD treatment, a multitude of barriers exist that could prevent access to patients who need them most. (https://www.mdedge.com/hematology-oncology/article/219361/anemia/new-sickle-cell-drugs-give-hope-access-remains-barrier)

The novel therapies on the market are more expensive than hydroxyurea – in some cases significantly so. However, providers says the benefits of these novel drugs far surpass the costs for them, both in terms of quality of life and financial impact on savings from hospitalizations and other aspects of care and productivity improvements.

Sickle cell disease has always been costly to manage – in fact a single hospitalization can cost $10,000. (https://www.mdedge.com/hematology-oncology/article/219361/anemia/new-sickle-cell-drugs-give-hope-access-remains-barrier)

Many SCD patients are insured through Medicaid because the disease leads to disability that prevents education and work. Those who are able to work often are able to do so for fewer years because of extreme pain and tiredness, frequent hospitalizations, and organ damage, which ultimately result in ongoing and even permanent disability. (https://www.mdedge.com/hematology-oncology/article/219361/anemia/new-sickle-cell-drugs-give-hope-access-remains-barrier)

Patients on several of the newer therapies experience delays – sometimes for months – in access due to prior authorizations.

As new innovations for SCD – including gene therapy – come to market, access is expected to be a significant issue. Such therapies would be provided to patients several times over the course of months but would not be needed as maintenance therapy for the rest of the patient's life. They could – if approved – offer profound gains in outcomes for people living with SCD, however their costs would likely be exponentially greater than current therapies on the market.

Developers of these potentially revolutionary innovations are working with policymakers to consider options that would allow access to people in need of the therapy. Potential access solutions include value-based payment (VBP) models, which tie payment for all or part of a therapy to its actual performance in patients. Such models can remove the financial uncertainty payers experience from paying one-time prices.

With so much promise at stake for the many people in the U.S. living with SCD, and the many others who will be faced with the disease in years to come, it is incumbent upon federal and state policymakers to help remove existing access barriers before they prevent any single individual from accessing these innovations.

Now is the time to bring about policy change that will deliver on the promise of innovation for people living with SCD today and born with the devastating disease in the future.

Tammy Boyd is the Chief Policy Officer & Counsel. To follow our progress on these important initiatives, learn more about our work and join us, visit www.bwhi.org.

Tackling Sickle Cell Disease with Policy

Tammy Boyd, JD, MPH

Tammy Boyd, Chief Policy Officer & Counsel, Black Women's Health Imperative

An expectant Black mother in America lives with the fear that her baby has a 1 in 13 chance of being born with sickle cell disease (SCD), and that her child may suffer a lifetime of debilitating medical conditions and live only into his 40s. African Americans are disproportionately impacted by SCD, and it is likely one of the underlying conditions that is responsible for the higher rates COVID-19 illness and mortality among Black populations in the United States. Although data is just beginning to be collected, findings suggest that people who have SCD and become infected with COVID-19 are at a high risk of experiencing a more severe illness and an increased fatality rate. Similar to other co-morbidity illnesses Black Americans disproportionally face, social determinants including socioeconomic status, implicit health bias and healthcare access contribute to the ongoing challenges impacting people with SCD .

The Black Women's Health Imperative, which promotes physical, mental and spiritual health, and well-being for the nation's 21 million African American women and girls, recognizes and understands the dire health consequences that both SCD and now COVID-19 have on our communities. As a top priority, we are addressing the challenges facing those living and battling these diseases by using our broad-based reach and power to advocate for policies that provide more equitable and adequate access to treatments for Black patients and other vulnerable people in this country.

Previously, there was just one drug for people living with SCD – hydroxyurea – three new drugs have been approved since 2017. Each of these new treatments can be used as monotherapy, or in combination with hydroxyurea, to provide additional pain and hospitalization reduction and anemia improving benefits. There are also alternative options for patients for whom hydroxyurea therapy is inappropriate. According to a report published in 2019, 17 new treatments are being developed. Despite these exciting advancements in SCD treatment, a multitude of barriers exist that could prevent access to patients who need them most.

Sickle cell disease has always been costly to manage, in fact, a single hospitalization can cost $10,000. Many SCD patients are insured through Medicaid because the disease leads to disability that prevents education and work. Those who are able to work often are able to do so for fewer years because of extreme pain and tiredness, frequent hospitalizations, and organ damage, which ultimately result in ongoing and permanent disability.

. As new innovations for SCD including gene therapy come to market, access is expected to be a significant issue. Such therapies would be provided to patients several times over the course of months, but would not be needed as maintenance therapy for the rest of the patient's life. If approved they could offer profound gains in outcomes for people living with SCD; however, their costs would likely be exponentially greater than current therapies on the market. We are imploring federal and state policymakers to remove existing access barriers before they prevent anyone from receiving new treatments for SCD.

Black Women's Health Imperative formed a Sickle Cell Disease Diversity Alliance charged with increasing awareness with an extensive education initiative around sickle cell disease. The organization also recently launched a Rare Disease Diversity Coalition to identify and advocate for evidence-based methods to ease the disproportionate burden of rare diseases on communities of color. We are harnessing the power of all these partnerships to ensure that policymakers hear our voices and are moved by our collective strength.

Ultimately, what is key is access to quality, affordable, and innovative approaches that provide comprehensive health care for Black women and girls—and everyone in this country. We will not be silent until we bring about policy change that will deliver on the promise of innovation for people living with SCD today and born with this devastating disease in the future.

Tammy Boyd is the Chief Policy Officer & Counsel. To follow our progress on these important initiatives, learn more about our work and join us, visit www.bwhi.org.

One Nurses Perspective on Sickle Cell—Facing Sickle at its "Finest"

Deja Turner RN, BSN

Deja Turner is currently an Oncology Nurse Navigator at the University of Chicago, working with the benign hematology and sickle cell population. Her previous clinical background consists of gynecology oncology and acute rehab nursing. Deja has participated in community outreach that includes women's education, early prevention and detection, and student mentorship. She has also received a grant to discuss topics related breast health in underserved communities. Her topics of interest include controversial issues impacting quality of life and "new generation" or millennial issues faced as a new or younger nurse.

Let us talk the truth of what it is like to have Sickle Cell Disease (SCD). Effecting 100,000 Americans, primarily African Americans with a small population effecting 1,400 Hispanic Americans (NIH,2020), this congenital blood disorder develops as one abnormal hemoglobin genes comes from each parent causing crescent like blood cells to block the flow of blood throughout the body. Many individuals are not aware that there are several forms of this blood disorder; expanding the spectrum in which sickle cell can present and how pain crisis are presented and the damage that sickle cell does to the organs over time.

Being a nurse navigator working primarily with the sickle cell population, it appears that the sickle cell population has a stigma. As a nurse who has practiced in oncology, the continuity of the oncology population has a higher standard of practice from the care given to those who present with sickle cell disease, providing around the clock pain management to oncology patients without regard. However, there is failure to realize, after many years of prescribed opioids, it can be difficult to manage pain crisis as the body has body adjust to dosages. Often times patients report having sickle cell crisis and their pain is not resolved after self-medicating prescribed opioids and reporting to the emergency room due to unresolved pain. Unfortunately, there is no way to determine how painful pain crisis affect each individual, as no person's pain is identical. Opioids are prescribed to help manage chronic and acute pain for a short term for a lifelong pain and disease. Years on pain medications, the chances heighten in which a stronger dose of pain medication will be prescribed, causing mediation dependency. Society has frowned upon the opioid epidemic; however, the medical industry relies on a prescription to be the solution to "help" the sickle cell population. Providers who do not specialize in this population, do not know how to manage the complex needs of this population as pain mediation alone cannot dissipate the pain indefinitely.

Contrary to opinions of the sickle cell population, pain should be treated according to the patient's history and assessment. It is often viewed, pain medication is all SCD patients want, however the complexity of this disease is ignored. The complexity of this disease is not limited pain but includes, vaso-occlusive crisis, priapism in the male counterpart, acute chest syndrome, apheresis due to high levels of iron and frequent blood transfusions leading to frequent hospital admissions and emergency room visits.

In hindsight, there is failure to realize this blood disorder can hinder the functionality of the organs in the body resulting in tissue damage. Healthy blood cells live for 120 days, unlike the sickled cells; blood cells live days at a time. According to the CDC Grand Rounds: Improving the Lives of Persons with Sickle Cell Disease, Frequent and rapid cell death reduces the oxygenation of blood flow to organs. This decreases the time blood and blood able to be filtered through the spleen, subjecting this population to an increased risk of infections. Hepatic functionality is targeted, lack of healthy tissue cells results in tissue deprivation, skin damage that results in non-healing skin ulcers.

Sickle cell like any other disease or diagnosis should be treated without the stigma of opioids being the solution to sickle cell or that this population is solely seeking pain medications. This diagnosis should be held in regard to the complications that arise when this disease is not managed properly and the events that are taking

place within the organ system. Options for effective treatment should be thoroughly evaluated when underlying issues are causing the crisis, pain related to primary and secondary health issues related to sickle cell and the patient is left partially managed.

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Lives with Sickle Cell Disease Matter

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Today the emphasis on lives that matter has reached global attention with multidimensional perspectives. One perspective pertinent in this hour is the lives of those living with sickle cell disease (SCD). The significance of any disease is inherent in the population affected, impact on quality of life, and resources allocated to remedy its effect. The trajectory of individuals living with SCD and its variants will show benefit when the history and characteristics of this disease emerges to the global forefront among all lives that matter.

SCD involves just a few of the over 1000 genetic variants of hemoglobin possible in the red blood cell (RBC). Sickle cell anemia (SCD-SS) occurs when both genes inherited are hemoglobin S. Sickle cell disease SC (SCD-SC) occurs when one gene makes hemoglobin S and the other gene makes hemoglobin C. Other common types of SCD have one gene for beta thalassemia and the other gene with hemoglobin S (SCD-S-beta-thalassemia), SCD-SO^{Arab}, SCD-SD^{Punjab}, and SCD-SE. Inheriting one gene for hemoglobin S and the other gene with normal hemoglobin A is called sickle trait, which is not a sickle cell disease.

The sickle hemoglobin changes many properties of the RBC: deformation into a sickle shape causing hypoxia, oxidant membrane damage that triggers thrombosis and increased RBC adhesion, and overall shorter lifespan for the sickled RBC. These characteristics impair the ability of the sickled RBC to perform metabolic, mechanical, and chemical transactions necessary at the macroscopic and cellular level for tissue homeostasis. The destruction of RBCs (hemolysis) leads to more oxidant stress, inflammation, and vascular damage. All of these pathophysiologic processes lead to organ damage, immune compromise, shortened life expectancy, and diminished quality of life when left untreated.

Those living with SCD and its variants have their origins in the African Continent with later expansion to India, Arabian Gulf, Asia and the North Americas. Although the exact number of individuals with SCD is unknown, SCD is estimated to affect millions of individuals worldwide, making it the most common autosomal recessive genetic disorder in the world. According to The Sickle Cell Coalition, more than 90% of children with SCD do not survive to adulthood in countries with poor resources; in some areas of sub-Saharan Africa, eastern Saudi Arabia and central India the prevalence of SCD is as high as 40%. Finally, by the year 2050 a 30% growth in SCD diagnoses is expected globally. SCD in developed countries like the United States and Jamaica have a median survival age of 45–55 years or 20-30 years shorter than those without SCD.

The U.S. Centers for Disease Control and Prevention estimates that:

- SCD affects approximately 100,000 Americans.
- SCD occurs in about 1 out of every 365 African-American births.
- SCD occurs in about 1 out of every 16,300 Hispanic-American births.
- About 1 in 13 African-American babies are born with sickle cell trait (SCT).
- Among the children with SCD, 1% died as a result of SCD-related causes during the first 3 years of life.
- In California and Illinois, by the end of 1995, the cumulative mortality rate was 1.5 per 100 African-American children with SCD.

The population affected by SCD is ubiquitous among people of color. The quality of life is impacted when specific organs begin to manifest the outcomes of the chronicity characterizing SCD symptoms which can emerge as early as 10-12 weeks of age. SCD is an invasive and unrelenting foe of humanity traversing the lifespan of lives that matter.

The fight against SCD and the challenge to develop remedies has evolved after decades of learning to comprehend its natural history. Although SCD was named in medical literature as early as 1910, only palliative treatment for symptoms was available. Not until 1998 did the first drug approved by the FDA to treat SCD become available. Another milestone was the adoption mandated newborn screening for SCD, leading to early recognition and intervention to reduce morbidity and mortality. Since 2017, three new drugs were approved by the FDA to treat SCD symptoms. Curative treatments are here, although in their early stages, including stem cell transplant and gene therapy. Directing persons with SCD to a Comprehensive Sickle Cell Disease Treatment Center is beneficial for lives with SCD because they matter.

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Cinderella (Cindy) Famutimi received a Bachelors of Science in Biology in 2017 from Hobart and William Smith Colleges in Geneva, New York. Shortly after that she joined the Sickle Cell Disease Implementation Consortium (SCDIC) working from their Chicago location as a member of the Improving Sickle Cell Care for Adolescents and Adults in Chicago (ISAAC) team. Since then she continued her education and recently received her Bachelors of Science in Nursing from Loma Linda University School of Nursing in Loma Linda, California.

Lewis Hsu is a pediatric hematologist at University of Illinois at Chicago with a career devoted to sickle cell disease, both clinical and translational research. His immersion in "team science" in sickle cell disease includes community health workers, implementation science, health education, and global community engagement. His volunteer service includes Vice Chief Medical Officer of Sickle Cell Disease Association of America and global experience at 3 sites in Nigeria plus Brazil.

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Advancing the Health Literacy of People with Sickle Cell Disease: The Path Forward

Julia O'Brien, BSN, RN
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While health literacy is recognized as a social determinant of health and is a recognized public health priority, little is known about how health literacy affects people living with sickle cell disease (SCD) and its contribution to their health and well-being. According to the U.S. Department of Health and Human Services, health literacy is characterized as an individual's ability to obtain, process, and understand health information and services to make appropriate health decisions. Low health literacy impacts a broad array of persons and challenges how individuals navigate through healthcare systems, interact with healthcare professionals, and make informed choices about their health, which predisposes persons with low health literacy to disparate health outcomes. The impact of low health literacy has substantial and longstanding effects on the health of individuals positioning it as a public health and national research priority. Yet, in the context of SCD which predominately affects African Americans, the focus on patient, provider, and organizational strategies to address health literacy is relatively overlooked yet is critical to advancing of the health and well-being of those living with SCD. This article will summarize the current state of research focused on health literacy as it pertains to persons living with SCD, and provide recommendations for further research and clinical practice innovation.

Similar to other populations of persons living with chronic conditions, low health literacy among people with SCD impacts the self-management behaviors and quality of interactions with healthcare providers that in turn influence the health behaviors and outcomes of this medically disenfranchised group. Due to a complex interplay of social and biological determinants, low health literacy among persons living with SCD is prevalent and presents a significant challenge for the attainment of health and other dimensions of equity, such as socioeconomic status and education (Bhatt et al., 2019; Caldwell et al., 2018; Perry et al, 2017). Although the extant literature is inconclusive on the link between health literacy and the healthcare resource utilization among persons with SCD, it is evident that health literacy is associated with an individual's understanding of SCD—a critical component for decision making and self-management behaviors. Yoon & Godwin (2007) also confirm that higher levels of SCD knowledge is associated with high states of self-efficacy toward self-managing their condition. The prevalence of low health literacy among persons with SCD and the expanding literature providing evidence on the association of health literacy with key contributors to effective self-management behaviors has substantiated the importance of health literacy research for this vulnerable population.

Our understanding of how to effectively address the impact of health literacy on key contributors to self-management behaviors, such as patient-provider communication, decision making, and self-management, is urgently needed to improve the quality of care and the health of persons with SCD. Presently, the existing literature exploring the associations among health literacy, patient-provider communication, decision-making and self-management is relatively nascent. Given what we know about association of low health literacy with these key contributors to self-management behaviors, it can be logically assumed that low health literacy is already contributing to reduces states of self-management that can result in poor health states among persons with SCD. Beyond person-level research on health literacy, there is minimal evidence on how healthcare organizations may institute practices that may enhance the quality of care and health outcomes of this medically and socially vulnerable cohort of care recipients. Unraveling the effects of health literacy and identifying effective and sustainable solutions to improve care for persons with SCD will require research that explores how health literacy across multiple levels (e.g., individual, interpersonal, organizational, and community) influence self-management behaviors and health outcomes.

As we move forward, future work regarding the health literacy of those living with SCD must use a systems approach to address the individual, organizational, and community factors that impact self-management behaviors and health outcomes. Helping individuals with SCD improve their health literacy will support their agency as decision-makers, and is in line with Healthy People 2030's goals of reducing health disparities and promoting well-being. While the relationship between health literacy, patient-provider communication, and self-management skills and outcomes in

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the context of SCD needs further investigation, intervention studies implementing existing interventions from other chronic disease populations should be considered. Practical solutions to tailor patient education and provider communication should be implemented as part of the clinical armamentarium of all clinicians providing care to persons with SCD and other chronic conditions.

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Health Disparities in Sickle Cell Disease

Yvonne M. Carroll, RN, JD

Yvonne Carroll is the Director of Patient Services, Hematology, at St. Jude Children's Research Hospital which treats more than 900 children with sickle cell disease. She is a Board Member and Past President of the International Association of Sickle Cell Disease Nurses and Professional Associates (IASCNAPA). She is on the Governor's Genetic Advisory Committee, has written numerous articles on sickle cell disease, and performed SCD research for more than 20 years.

Sickle cell disease (SCD) is the name for a group of disorders that have in common a hemoglobin S allele and either another Hemoglobin S allele or a second abnormal allele which causes polymerization of the hemoglobin and leads to chronic progressive disease complications. The most common types of SCD in the US are hemoglobin SS, SC, and Sickle Beta Thalassemia. SCD affects millions of people worldwide and more than 100,000 people in the US. The hallmark of the disease is excruciating pain, however cumulative organ damage is the cause of most mortality and morbidity in adults with SCD.

In addition to the stress of dealing with a chronic health condition, people with SCD are subjected to health disparities not seen in other conditions. According to an article by the Journal of the American Medical Association, the federal government provides less financial support for SCD research than for Cystic Fibrosis, (~$3 for CF to every $1 for SCD); even though 60,000 more people suffer from SCD than CF.[1] The funding disparity can help explain the paucity of drugs available for SCD. Only 4 FDA drugs are approved for SCD, and 2 of those, Oxbryta© and Adakveo©, were only approved in the last year. Also, there was almost a twenty-year span between the first FDA approved drug in 1998 and the second drug in 2017 (Hydroxyurea and Endari© respectively).

Health disparities for people with SCD are both systemic and environmental. According to the Centers for Disease Control Foundation, people with SCD have a lifespan that is 30 years shorter than those without SCD; adults ages 35-64 with SCD have three times the chance of having a stroke than African Americans without SCD; less than 70% of doctors accept Medicaid, however, more than 70% of people with SCD are on Medicaid; and people with SCD have longer wait times in the Emergency Department to see a doctor and obtain pain medication than those without SCD.[2]

Adding to the problem is the implicit bias in the healthcare system. The National Institutes of Health describes implicit bias as:

- Bias consists of attitudes, behaviors, and actions that are prejudiced in favor of or against one person or group compared to another.
- Implicit bias is a form of bias that occurs automatically and unintentionally, that nevertheless affects judgments, decisions, and behaviors.[3]

In a study in the Journal of General Intern Medicine, interns were given two hypothetical medical records for a SCD patient, one neutral and one with stigmatizing language. Interns had more negative attitudes toward the patient with the stigmatizing language in the record and their pain was treated less aggressively.[4] Unfortunately, these incidents happen all too often in the real world. 112 SCD patients surveyed felt that their race had an impact on the quality of the healthcare received.[5]

The lack of diversity among physicians exacerbates the problem. Only 6% of doctors in the US are African American while African Americans represent 13% of the population. Additionally, it has been shown that African American physicians tend to practice in more underserved community and engender more trust and comfort in African American patients.[6,7]

In addition to disparities in the healthcare system, SCD patients face environmental disparities.

The wealth gap between white and African American is larger now that it was 50 years ago. African Americans tend to live in poorer areas, with lower home values, more crimes, less hospitals, and fewer grocery stores than their white counterparts. Racism, redlining, and white flight may account for part of this phenomenon. It also may indirectly help perpetuate SCD. In an article in Pediatric Blood and Cancer, SCD cases were mapped for 20 years in one metropolitan area, the analyses found "that 48% of the SCD cases

resided in only six of the 37 residential ZIP codes, and using GIS mapping there were two clusters composed of two and four adjacent urban ZIP codes." The article found further that the rate of SCD was higher than the national average.[8]

The system will only change with concerted effort and diligence. Nurses can be at the forefront of diversifying and upending systemic bias in the treatment of people with SCD. Trust, communication, access, and overturning implicit bias are instrumental in breaking the cycle. Education and awareness can happen with active participation in diversity and inclusion efforts. Nurses are well poised to lead and fill these roles and raise awareness around the health disparities in SCD.

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Treating Sickle Cell Disease —The Role of African American Blood Donors

Yvette Marie Miller, M.D.

Dr. Yvette Marie Miller is currently the Executive Medical Officer for the American Red Cross Donor and Client Support Center. Her areas of interest include donor eligibility, donor recruitment in the African American community, donor education and equitable access to healthcare in underserved communities.

Overview

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States, affecting an estimated 100,000 Americans, the majority of whom are African American. The C-shaped red blood cells (RBC), hence the term sickle cell, become inflexible and clump together in small blood vessels and block the flow of blood and oxygen to the body leading to the complications of SCD such as repeated episodes of severe pain, organ damage, acute chest syndrome, stroke and even premature death. Additionally, these abnormal cells die prematurely leading to anemia. For many patients with SCD, blood transfusion is the primary method to treat or prevent the complications of the disease by reducing the hemoglobin S (HbS) level.[1] But for African American patients, blood transfusion itself can lead to complications. To avoid this, the best blood product match is likely to be identified in African American blood donors or donors of the same race or ethnicity. Now superimposed on this chronic medical condition, is the threat of the COVID-19 pandemic which has disproportionally affected the African American community, particularly those age ≥ 65 and those with underlying health conditions, specifically, cardiovascular disease, chronic lung disease and diabetes.[2] Patients with SCD often have underlying cardiopulmonary co-morbidities that may predispose them to poor outcomes if they become infected with COVID-19. The primary objectives of clinicians and healthcare providers of patients with SCD, is to maintain their health and wellness by continuing their usual transfusion treatment plans and to prevent emergency room visits which can exposure these vulnerable patients to COVID-19.

Treatment of SCD with Blood Transfusion Therapy

Blood transfusion therapy is a primary treatment for patients with SCD and is increasing due to expanded clinical indications, increased availability of RBC exchange and access to oral iron chelators to treat transfusion iron overload. A dreaded complication of multiple transfusions is alloimmunization. Patients with SCD have the highest incidence of RBC alloimmunization than any transfused patient population, for reasons that are not completely understood. However, one explanation of the high rates of alloimmunization is the disparate distribution of RBC antigens between donors primarily of European ancestry and patients with SCD primarily of African ancestry. Relatively large transfusion burdens, in combination with the inflammatory component of SCD are thought to play a role. RH genetic diversity in patients with SCD is an additional risk factor, with the majority having at least 1 RH allele that differs from those found in individuals of European descent. For this reason, the best blood product match for African American patients is likely to be identified in donors of same race or ethnicity. The use of phenotype-matched RBC does not prevent all Rh alloimmunization, but the frequency is lower. [3,4]

The Need for African American Blood Donors

In the U.S., African American blood donation rates are 25-50% lower than that of the Caucasian population. The majority of U.S. blood donors are Caucasian. Reasons for these differences are multifactorial and include fear and distrust of health care institutions,

increased deferral rates for low hemoglobin and inconveniently located donation sites. As the transfusion needs of patients with SCD increase, the demand for matched blood products from African American donors will also increase. When there is an adequate inventory of blood from African American donors, there will be a greater likelihood that a phenotype match will be found. Focus on donor recruitment and retention, addressing the historical lack of access to donation and enhancing community engagement and education may lead to higher donation rates.[5]

The Impact of COVID-19

The COVID-19 pandemic has also had a profound impact on the presentation of African American blood donors. In some areas, the presentation rate decreased in excess of fifty percent. Even though blood donation was deemed an essential service, great concern over the high rates of infection and mortality in the African American community and following the CDC recommended guidelines to prevent exposure to the virus, will likely continue to have an impact on donor presentation. However, addressing the longstanding the lack of trust in health care institutions, increasing access to donation and focusing on community engagement and education may ultimately lead to higher blood donation rates.

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Emerging Therapies for Sickle Cell Disease

Misty D. Evans, APRN, CPNP-AC, BMTCN
Haydar Frangoul, MD, MS

Sickle cell disease (SCD) is the most common inherited blood disease with homozygous frequency of 1 in 400 African American births in the United States. The feature characteristic of sickle cell disease is the polymerization of hemoglobin S resulting in stiff, sickle shaped red blood cells. The distorted red blood cells obstruct blood vessels and compromise circulation. Insufficient blood flow to tissue results in severe pain, and over time, organ damage. Affected individuals may experience significant complications, such as infection, veno-occlusive pain crisis (VOC), acute chest syndrome and cerebrovascular accidents. Despite improved survival for children, adult patients with sickle cell disease have a 3-6 fold increase risk of dying compared to age matched control group. Treatment for patients with sickle cell disease includes supportive care, penicillin prophylaxis, transfusion treatment, hydroxurea and the recently approved therapies including crizanlizumab and voxelotor.

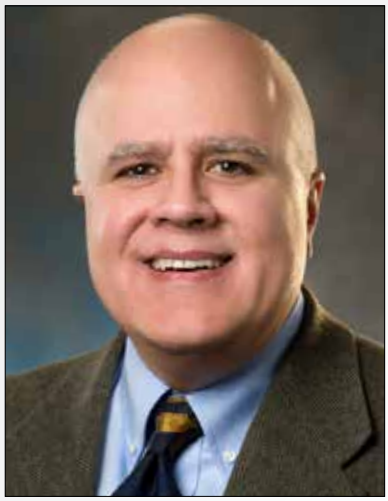
The only curative therapy for sickle cell disease is allogeneic hematopoietic stem cell transplant. Transplantation involves significant risks including graft versus host disease, infection, organ failure and graft rejection. Additionally, less than 15% of patients have an HLA identical donor, which further limits the option for transplantation. Transplant from unrelated donors have been associated with significant potential complications. More recently, encouraging results for haploidentical transplant have been reported by our group and others.

A key treatment approach for sickle cell involves promoting expression of fetal hemoglobin (hemoglobin F or HbF). Hemoglobin F is present in fetal development and infancy, but is suppressed in adults. Hemoglobin F interferes with the polymerization of hemoglobin S (HbS), thereby inhibiting the sickling of red blood cells. Increasing the production of hemoglobin F can significantly reduce the severity and frequency of sickle cell symptoms. Some adults affected by SCD express unusually high levels of HbF and present with a much milder course of SCD. The phenomenon was named hereditary persistence of fetal hemoglobin (HPFH). Case reports and small studies show that people who are homozygous for the sickle variant, but also have high expression of HbF through adulthood (HPFH), have few or no SCD symptoms despite having HbS concentrations >60%. In 2007, a series of genome-wide association studies (GWAS) identified BCL11A gene as a modulator of HbF levels. In animal models, disruption of BCL11A gene in erythroid progenitors can result in increased production of hemoglobin F.

As a result, researchers have identified a revolutionary method to increase production of hemoglobin F through CRISPR-Cas9 gene editing. In this process, stem cells are collected from the patient and then gene edited to disrupt the BCL11A gene in erythroid progenitors. Thereafter, the patient receives myeloablative chemotherapy conditioning regimen and then the edited stem cells, known as CTX001, are infused back into the patient's bloodstream.

In June 2019, the first patient with sickle cell disease received CRISPR-Cas9 gene editing stem cell therapy on clinical trial at our institution (NCT03745287). Prior to study enrollment, the patient had seven vaso-occlusive crises and received five packed red blood cell transfusions per year. Nine months following CTX001 infusion, the patient was free of any VOCs, was transfusion independent and had total hemoglobin levels of 11.8 g/dL. The individual has sustained elevation of hemoglobin F with 46.1% fetal hemoglobin, and 99.7% of the red blood cells have fetal hemoglobin. The significant advantage of this approach is using the patients' own stem cells. This will eliminate the need to identify a matched allogeneic donor and make this treatment available to all patients. Additionally, this therapy does not require any immune suppression, or the potential risk for graft versus host disease. These results are encouraging and require additional study with a larger number of patients to establish safety and efficacy of this approach.

Misty Evans is an Assistant Professor at Vanderbilt University School of Nursing and practices as a Nurse Practitioner at TriStar Centennial Children's Hospital/Sarah Cannon Research Institute. Her clinical interest is hematology-oncology and stem cell transplant care in pediatric, adolescent and young adult patients. She serves as Director at Large for the Association of Pediatric Hematology Oncology Nurses and is co-chair of the American Society for Transplantation and Cellular Therapy Advanced Practice Provider Sig group.



Dr. Haydar Frangoul specializes in pediatric hematology-oncology and stem cell transplant at TriStar Centennial Children's Hospital and Sarah Cannon Research Institute. His research and clinical work center on hematopoietic stem cell transplant with special interest in non-malignant diseases including sickle cell disease. His group focuses on allogeneic transplant for sickle cell disease and gene editing for patients with sickle cell disease and thalassemia. He has authored more than 130 peer-reviewed manuscripts.

The Role of Music Therapy in Sickle Cell Disease

Samuel N. Rodgers-Melnick, MT-BC

Samuel N. Rodgers-Melnick is a music therapist with University Hospitals Connor Integrative Health Network in Cleveland, OH, where he provides music therapy services to hematology and oncology patients at Seidman Cancer Center. His research focuses on the effects of music therapy on pain management and transition outcomes in adults with sickle cell disease.

The first time I met someone with sickle cell disease (SCD) was in 2012 during my music therapy internship at University Hospitals Seidman Cancer Center. Every week, I facilitated a group drumming session for adults with SCD admitted to the medical oncology unit, their family members, and nurses. Even while experiencing significant pain, these patients would come for an hour to participate in drumming, singing, songwriting, and discussions of coping skills. This was where I first observed how music therapy could not only provide a means of coping with hospitalization, but also lead to significant reductions in patients' pain ratings and opportunities for positive shared experiences between patients and nursing staff. Working with these individuals also helped me understand many of the widespread challenges in healthcare such as the inadequacy of opioids in treating severe multidimensional pain, the ways in which systemic racism promotes healthcare disparities, and the difficult transition from pediatric to adult care for individuals with chronic illness. At that time, there were no systematic studies of music therapy in individuals with SCD. Therefore, we developed a plan to research the effects of music therapy on two major areas of concern for individuals with SCD: the transition from pediatric to adult care and pain management.

In 2014, we developed the Build-Educate-Advance-Transition in-Sickle cell disease (BEATS) program to assist adolescents and young adults with SCD in building self-efficacy and self-management skills to navigate the transition to adult care. At each BEATS session, we used music therapy interventions to teach specific skills. For example, participants learned songs to memorize their baseline lab values – *"7.6 is my baseline hemoglobin/ the part of my red cells that does the O2 loadin"* or learn medication management skills – *"make sure you have a daily reminder/ like an alarm on your phone that's loud like a grinder."* Other BEATS sessions provided opportunities to practice communication strategies to use in the Emergency Department, develop a pain action plan, and understand the processes involved in blood transfusions. Participants in our initial research demonstrated improved SCD knowledge and clinic attendance over the course of the study (Rodgers-Melnick et al., 2017).

To address pain management, we conducted a series of studies to 1) investigate the effects of a single music therapy intervention during a pain crisis, 2) understand how adults with SCD use music, and 3) provide patients with practical music interventions to manage daily pain and improve quality of life. In our first study, patients receiving treatment for an acute pain crisis were randomized to either 1) a music therapy session, 2) music listening (no therapist), or 3) control (no music). During the music therapy session, the participant and music therapist improvised notes on an iPad keyboard along with personalized music for 20 minutes. These participants reported significant improvements in pain intensity and mood compared to control. Quantitative and qualitative data from this study suggested that making music with a music therapist produced more benefits that music listening alone (Rodgers-Melnick et al., 2018).

In a subsequent survey study, we observed that the more strategies adults with SCD used along with music listening (e.g., deep breathing, singing, taking a hot bath, prayer), the more helpful participants found music for reducing pain (Rodgers-Melnick, Gam, Debanne, & Little, 2020). Knowing that many individuals with SCD experience daily pain and impaired quality of life (McClish et al., 2009), our current research endeavor is to investigate the feasibility, acceptability, and preliminary efficacy of a 6-part music therapy protocol on pain, quality of life, and self-efficacy in adults with SCD and chronic pain. In this study, participants are taught a series of personalized music exercises (i.e., music-assisted breathing, progressive muscle relaxation, imagery, active music making) that

can be accessed via their mobile devices. Our preliminary data support the feasibility and benefits of this intervention for improving several quality of life domains.

In doing this work, we have demonstrated that music therapy can be a powerful tool to aid in improving the transition to adult care, decreasing pain, and improving quality of life for adults with SCD. However, this approach requires more than the music itself. Just as nurses perform a crucial role in the delivery of medical interventions, music therapists are essential in tailoring music to patients' needs and preferences, engaging patients in the music intervention, responding to patients' mental and emotional needs in the moment, and providing a structure for patients to incorporate music exercises into their daily lives.

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Social media messages

"Working with these individuals helped me understand many of the widespread challenges in healthcare such as the inadequacy of opioids in treating severe multidimensional pain, the ways in which systemic racism promotes healthcare disparities, and the difficult transition from pediatric to adult care for individuals with chronic illness."

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"In our first study, patients receiving treatment for an acute pain crisis were randomized to either 1) a music therapy session, 2) music listening (no therapist), or 3) control (no music). During the music therapy session, the participant and music therapist improvised notes on an iPad keyboard along with personalized music for 20 minutes. These participants reported significant improvements in pain intensity and mood compared to control."

Sickle Cell Awareness Month

Patricia Lyons, MSN, RN

Patricia A. Lyons is a graduate of Grady Memorial Hospital School of Nursing (Diploma), Medical College of GA (BSN), University of Alabama at Birmingham (UAB) , MSN. Patricia retired from the US Navy after spending 24 years. She is employed at UAB Hospital as a Pre Transplant Coordinator.

September has been designated as Sickle Cell Awareness Month. It is a time set aside by Congress to focus attention on the disease, and to educate the public on the treatment options and research outcomes available. The theme for this year is *Sickle Cell Matters.* Sickle cell disease (SCD) matters because it affects people of many races, but disproportionately African Americans, causing early mortality, debilitating strokes and pain crises, crippling rounds of depression and hopelessness, and for many, financial ruin because of loss of health care and/or inability to pay for expensive medications or treatments. SCD matters because many require monthly blood transfusions just to be able to carry out those activities of daily living that most of us take for granted. SCD matters because today, with several ongoing research studies, we are closer than we have ever been to finding a cure so that those afflicted might be cured and able to just live a normal life without pain, labels, or judgments.

According to the Sickle Cell Disease Association of America, Inc, there are five facts concerning SCD that they want you to know:

1. The hallmark of SCD is severe unpredictable pain, sometimes requiring high doses of narcotics.
2. The vast majority of individuals live well into adulthood (but average life expectancy is generally in the 40's).
3. Sickle cell trait is not a disease; it is generally an asymptomatic carrier state. One of 13 African Americans has the trait, and many are unaware that they carry the trait. If both biological parents have the trait, there is a one in four chance of having a baby with SCD.
4. SCD does not only affect black people, but is seen in people of many races.
5. Bone marrow transplant is not a universal cure; not all individuals with SCD are eligible, and there are associated risks.

The Sickle Cell Foundation of Birmingham sponsored its Annual Sickle Cell Walk on September 12, 2020. Because of the rapidly evolving coronavirus 19 pandemic, this year's event was a virtual walk and was also the first time the walk had occurred as late as September. The walk is usually scheduled during the month of May. Because SCD matters, please consider helping by visiting the Sickle Cell Foundation's website to make a financial donation to the Sickle Cell Foundation and by donating blood to the American Red Cross. You can make a difference because Sickle Cell Matters!

I would like to acknowledge the loss of a champion for the local sickle cell community earlier this year. Ms. Sharon Lewis, Executive Director of the Sickle Cell Disease Association of Central Alabama chapter, served the sickle cell community for over 40 years. One of her many accomplishments was that she and her staff worked to raise one million dollars to help establish the first comprehensive adult sickle cell clinic at the University of Alabama's Kirklin Clinic. She will be missed but never forgotten.

Patricia Lyons, RN is chair of the sickle cell disease initiative for the Birmingham Black Nurses Association.

VOC Day, a Patient Centric Endpoint for Evaluating Treatment of Sickle Cell Disease

Debra Pittman MS
Steven Arkin MD
L Maria G Kelly RN

Sickle cell disease (SCD) is a multisystem disease affecting approximately 100,000 individuals in the United States, predominantly of African ancestry. It is caused by a mutation on the ß-chain of adult hemoglobin (Hb A) resulting in Hb S.[1] As a result of this mutation, when in the homozygous or compound heterozygous state, Hb S polymerizes once it gives up oxygen in the tissues, resulting in red blood cell sickling, oxidant damage, increased adhesion of red cells to other cells, hemolysis of red blood cells and activation of inflammatory and coagulation pathways.[2] Clinical consequences arising from obstruction of the microcirculation, and/or the underlying chronic hemolytic anemia include episodes of vaso-occlusion (VOC), chronic hemolytic anemia, splenic infarction, stroke, avascular necrosis, skin ulcers, priapism chronic renal disease and pulmonary hypertension. Disease manifestations dramatically impact quality of life and, in aggregate, shorten average lifespan by 2-3 decades.[3]

VOC episodes are a prominent acute feature of SCD. They present as episodes of pain and inflammation at one or multiple sites, of varying degrees of severity, occur at varying intervals throughout life. are responsible for >90% of hospitalizations and result in significant morbidity, mortality, and interruption of daily functioning.[4] Patients description of pain crisis include pain worse than usual, fatigue, limitations in social, physical, and daily functioning, and seeking medical attention when symptoms become more severe.[5] For one patient the impact described was “Initially I’d say that you’ll feel very tired and that your body will feel weak and then you’ll feel like this throbbing pain in your joint areas, like your knees, like around your shoulders.” Patients describe the VOC episodes interfering with daily functioning “I’m not always able to interact with peers. Since I’m not able to, you have to depend on others and if you are[an] independent person, it messes with your psyche”. Over the course of a year, about 60% of patients homozygous for HbS will have at least one severe VOC requiring a clinic visit or hospitalization.[5]

VOC is often viewed through the lens of medical resource utilization (facility visit/ utilization), and in that context, has been sufficient to support clinical evaluation of several drugs that reduce the frequency of VOC.[1] However, this definition substantially underestimates the impact of the disease on affected patients and fails to capture VOC episodes that may be treated at home. In a non-interventional clinical trial entitled Pain in Sickle Cell Epidemiology Study (PiSCES), investigators collected data on a daily basis, directly from patients with SCD, for presence of VOC (crisis day), pain severity (10 point scale), medical utilization and location of medical care using daily entries in paper diaries.[6] In the analysis of diary entries only 12.7% of days were reported as VOC with medical utilization whereas 38.3% were reported as VOC without medical utilization indicating that a substantial portion of the VOC impacting patients are invisible to the medical system. These observations underscore the limitations of defining VOC based on medical utilization and prompted Pfizer to develop VOC Day as a patient centric approach to evaluate the daily burden of sickle cell VOC.

Building on the experience of the PiSCES trial, Pfizer colleagues working with investigators at Children’s Hospital of Michigan, conducted the Evaluation of Longitudinal Pain Study in Sickle Cell Disease (ELIPSIS) study to test novel tools to identify and document the natural history of VOCs occurring in SCD patients before, during, and after a self-reported VOC event. A patient-focused definition of VOC, the VOC Day, was developed to capture the patient experience of a pain crisis that was managed either at home, in a clinic, in the emergency department, or in the hospital. In this innovative at-home 6-month study, 35 individuals with SCD provided longitudinal measures of pain, fatigue, function, presence (VOC Day) or absence of VOC pain and medication use on a daily basis using an electronic diary.[7] The diary device directly captured from the patient, daily pain, fatigue, function, medication use and any VOC days. Self-reporting of VOC in real time enabled a mobile phlebotomy team to collect blood specimens within 24 and 48 hours of VOC onset and following VOC resolution, for comparison with specimens collected at baseline and during non-VOC periods. Mobile phlebotomy enabled a more patient-centric approach with blood draws in a home setting. A total of 286 days were reported with VOC >4 hours in duration of which only 58 days (20%) resulted in healthcare utilization. VOC Days had significantly higher pain and

Debra Pittman is currently a Research Fellow and Hematology Lead in Pfizer's Rare Disease Research Unit. Her early training was in molecular biology, but throughout her career she has worked on models of disease and the translation of nonclinical studies into early clinical development as a research project leader and nonclinical pharmacology lead. She is currently developing improved therapies for hemostasis and hematological diseases.

Steven Arkin is a Pediatric Hematologist with a career long interest in developing new treatments for non-malignant hematologic diseases. Over the past 15 years he has directed numerous clinical research programs, most recently with Pfizer's Rare Disease Research Unit.

L Maria G Kelly RN is the Patient Advocacy Director at Pfizer's Rare Disease Research Unit. She has over 15 years of working with rare disease patients, caregivers and advocacy organizations.

fatigue scores while measures of daily function were significantly decreased. At-home VOCs have a substantial impact on patients, ELPSIS demonstrated the potential and feasibility of a more patient-centered assessment of SCD VOC events. Involvement in a study wherein data was self-reported with mobile study visits to the patient's home was well received by study participants. In a telephone interview one study participant related that "Being in the study was a good thing, not a problem at all. I set time aside every day and didn't find it a burden.", and on the properties of the electronic diary "It was easy to use. I actually thought it was cool;" in addition from the patient perspective "It asked about how your day was going. You put your password in it and there were options, scales, and asked about your health."

Results for the VOC Day indicate that patients can reliably report VOC pain, distinguish it from other types of pain and can report secondary measures that assess impact of the VOC. Interviews with study participants and their caregivers were subsequently conducted to confirm concepts important to patients and establish content validity of the electronic diary questions. Based on ongoing discussions with the FDA, the electronic diary questions are being refined and are planned for implementation as a patient reported endpoint to evaluate efficacy of new treatments for of sickle cell disease. Benefits of the VOC Day endpoint include a more comprehensive assessment of disease (and treatment) impact on the patient and enabling the voice of the patient in assessing effectiveness of new treatments.

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Important Considerations for Nurses About the Management of Patients with Sickle Cell Disease during the COVID-19 Pandemic

Coretta H. Collins, MSN, FNP-BC

Coretta H. Collins is a family nurse practitioner in Birmingham, Alabama, with over 13 years of nursing experience. The last 7 years have been in Hematology & Oncology. She graduated with honors from The University of Alabama at Birmingham in 2012 with a Master of Science in Nursing and she is professionally affiliated with Hematology & Oncology Associates of Alabama and Brookwood Baptist Medical Center in Birmingham, Alabama.

Sickle cell disease (SCD) is an inherited blood disease affecting hemoglobin where red blood cells become sickle or crescent shaped instead of round. This malformation of the cells and decreased oxygenation cause organ damage and painful vaso-occlusive crises (VOCs) via a multifactorial process extending beyond sickled red blood cells (Conran, Franco-Penteado, & Costa, 2009). Recurrent VOCs are the hallmark of SCD and patients face unique challenges, including many comorbidities, due to the nature of the illness. The unfortunate arrival of COVID-19 further intensifies these challenges. Nurses play a vital role in helping patients with SCD optimize their health in the hope of preventing COVID-19 infection and hospitalization. Some of the ways that nurses can help are listed below.

Providing COVID-19 Education

Many patients with SCD are immunocompromised and have an increased likelihood of complications if they develop an infection. Infections, such as COVID-19, can lead to worsened SCD complications, including VOCs (Booth, Inusa, & Obaro, 2010). COVID-19 often affects the lungs and can contribute to compromising other organs (Cummings et al., 2020). An example of a severe complication is having a patient with acute chest syndrome (ACS) in addition to COVID-19. ACS is potentially life threatening and includes the symptoms of chest pain, fever, hypoxia, and lung infiltrates (Novelli & Gladwin, 2016). ACS has similarities to COVID-19, which could make treatment more difficult and decrease positive outcomes. Equipping patients with SCD with the necessary tools for prevention is paramount. This patient population should avoid crowds and interaction with those who are ill. It is especially important for patients to refrain from contact with persons who are showing any symptoms of COVID-19. Additionally, outings should be restricted to essential needs only. Encourage patients to have a designee for errands and to use options such as grocery delivery, if feasible. Otherwise, hand hygiene, wearing a mask, maintaining social distancing recommendations, and refraining from touching the face with contaminated hands are also helpful.

Online resources from the American Society of Hematology (ASH, 2020) and the Sickle Cell Disease Association of America (SCDAA, 2020) offer additional guidance on the management of patients with SCD during the pandemic.

Telemedicine Visits

Telemedicine visits are an excellent opportunity for many patients with SCD. This modality allows patients to remain safe at home as long as they are not currently experiencing any SCD complications.

For patients who are stable, it may not be necessary for laboratory work to be completed at each visit, further supporting the telemedicine approach. During telemedicine visits, providers and nurses are able to review medication management and encourage adherence, along with reemphasizing the importance of COVID-19 precautions.

Medication Adherence

Many patients with SCD are taking medications such as hydroxyurea and folic acid to assist in disease management. There are also two new medications available for patients with SCD. This is fantastic news because there have not been any medical breakthroughs in SCD for many years. The new medications, crizanlizumab-tmca and voxelotor, may have been initiated or planned for your patients. Remind patients that it is important to continue to take their medications as prescribed in an effort to reduce the likelihood of VOCs and disease complications. Furthermore, the SCDAA suggests considering prophylactically starting and/or optimizing existing therapies approved to reduce VOC frequency (e.g. hydroxyurea, L-glutamine and crizanlizumab-tmca) and the likelihood of requiring a health care visit, where patients could be inadvertently exposed to COVID-19 (SCDAA, 2020). Patients can be educated over the phone or with alternative communication devices. It is important for patients who have started taking these medications to continue them. Crizanlizumab is an intravenous therapy, so it has to be administered within the clinical setting. Because the infusion is relatively short, there may be more flexibility for patients to get in and out of the clinic faster, hopefully minimizing the risk of exposure.

Patients with SCD need to be encouraged to contact their healthcare team immediately if they experience any symptoms of COVID-19. As with common issues of SCD, early intervention is also best in the case of potential COVID-19. By working together and through active communication, nurses can positively impact the care of patients with SCD and aid in decreasing the risk of developing COVID-19.

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Acknowledgements

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A Local Chapter's Call to Action: Resilience, Mentorship and Membership Engagement

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Deborah Andrews, MSHSA, RN
Geneva Irby, RN
Carthenia Jefferson, RN, Esq.
Deborah Thedford-Zimmerman, MSN, RN, CWOCN
Deborah Walker, MA, BSN, NE-BC

Dr. Lindsey Harris assumed the presidency of the Alabama State Nurses Association (ASNA) on September 25, 2020 and made history as the first African American president of the state association in its 107 years of existence. Dr. Harris is a past president of the Birmingham Black Nurses Association (BBNA).

ASNA was founded in 1913 (ASNA, 2018). For over 100 years ASNA has existed to represent the nurses of Alabama. One of ASNA's inaugural initiatives involved the need for nurse licensure in Alabama, and in 1923 the organization called for creation of what has become the Alabama Board of Nursing. For decades ASNA has maintained a diverse membership of registered nurses, licensed practical nurses, and nurses from varied races and ethnicities. Despite the diversity of its membership, the organization had not elected an African American nurse as its president.

BBNA has been very supportive of ASNA, with members serving as officers and in leadership roles as committee chairs and convention delegates. BBNA is an active participant in ASNA's Annual Nurses Day at the Capitol, coordinating transportation and serving as session speakers. One of the past presidents of BBNA has served as chairperson of the state rally.

Despite BBNA's active engagement in all of ASNA's initiatives, it appeared to be nearly impossible for an African American nurse to advance to the president's seat. However, BBNA leaders felt that the time was ripe for change. While change is always difficult, institutional and cultural change can be insurmountable. BBNA leaders and members accepted this call to action and became more resilient after each failed attempt, while still supporting ASNA and maintaining its partnership with the organization. BBNA leverages that partnership to improve the health of Birmingham's residents. However, even with strong partnerships, there are opportunities for improvement and change.

Resilience is defined as the ability to bounce back from tough times, to have courage, and to connect effectively with others to bring about positive change (Webster's New World College Dictionary, n.d.). Thus, BBNA implemented its plan for change in the leadership of ASNA. Each year a BBNA member declared official candidacy for ASNA president, and each year we were unsuccessful. BBNA's candidates were all well qualified, experienced professionals, including past presidents of BBNA, board members of ASNA, board members of the National Black Nurses Association (NBNA), chief nursing officers, and nurse attorneys. With each setback, BBNA leaders and members rebounded and increased their professional engagement with the state organization. BBNA members actively recruited new members, encouraged members to serve as delegates, nominated nurses for professional awards, and supported the organization with vendors/exhibitors for scheduled events. Most importantly, in 2018, BBNA's current president stepped up and moved forward as a serious candidate. All of the aforementioned events constituted the thoughtful, painstaking plan that would lead to our ultimate success. Previous candidates supported and encouraged Dr. Harris, and members engaged in the process with renewed commitment.

BBNA has a long and successful history of mentorship and investment in students and the next generation of nurse leaders. This mentorship started with BBNA's founding members in 1989 and

continues to this day. The unique aspect about BBNA's mentorship approach is that students and new nurses are mentored by multiple members. Each mentor, official and unofficial, provides a different perspective to shaping a young member into a professional nurse and future leader. The objectives of BBNA's mentorship program are to (a) foster professional growth among mentees, (b) increase the number of students graduating into the nursing profession, and (c) increase student exposure to career choices.

In October 2018, BBNA mentors' efforts paid off with big dividends when its current young president, Dr. Lindsey Harris, became the first African American president-elect of ASNA. After 100+ years in the making, it did indeed take a "village." BBNA's efforts demonstrate leadership, advocacy, and mentorship in action.

Dr. Harris began her association with BBNA as a nursing student. Mrs. Geneva Irby, BBNA vice president emeritus, and other members took the young nursing student under their professional wings and groomed her for success and leadership. After receiving her nursing degree from Samford University, Dr. Harris earned her master of science in nursing as a family nurse practitioner and her doctor of nursing practice from the University of Alabama at Birmingham School of Nursing as BBNA continued to support, encourage, and nurture her in our local and national organizations. Dr. Harris has continued to grow with BBNA and NBNA. She has received BBNA chapter scholarships and the Minority Nurse scholarship. In 2011, Dr. Harris was recognized as NBNA Staff Nurse of the Year. In 2015 she received the NBNA Advanced Practice Nurse of the Year award, and was recognized in 2016 as a member of the next generation of nursing leaders with the NBNA 45 under 40 Award. She has held several positions with our state organization, including chair of the Commission on Professional Issues, Environmental Committee, delegate-at-large, and ASNA secretary.

BBNA past presidents, Mrs. Deborah Andrews and Dr. Carthenia Jefferson, helped to create the path for Dr. Harris to ascend to successive positions in ASNA and the eventual move into the top leadership position. BBNA leadership and members are to be commended for their professional resilience.

At its first chapter meeting after Dr. Harris' election as president-elect in 2018, BBNA celebrated Dr. Harris with roses, a congratulatory reception, and heartfelt testimonials. BBNA president emeritus, Deborah Walker, and vice president emeritus, Geneva Irby, reminisced about Dr. Harris' first days as a student member of BBNA. Dr. Jennifer Coleman reminded everyone that Dr. Harris was an undergraduate student of Dr. Coleman's at Samford University. Several members spoke of the dedication, commitment, and passion for nursing that Dr. Harris consistently demonstrates. BBNA members are indeed continuing to celebrate and cannot stop smiling!

The promotion of excellence in nursing is the mission of ASNA; and with the election of Dr. Lindsey Harris, the organization is now positioned to embrace its vision of being the professional voice of all registered nurses in Alabama. Congratulations to Dr. Lindsey Harris, ASNA president!

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Jennifer J. Coleman, PhD, RN, CNE, COI is professor of nursing at Ida Moffett School of Nursing at Samford University. She coordinates the nurse educator concentration courses in the doctoral program and teaches core doctoral courses. Dr. Coleman is chair of BBNA's mentorship program.

NBNA president, Dr. Martha A. Dawson, DNP, RN, FACHE is Director of Nursing and Health Systems Leadership, Coordinator of Nursing and Health System Administration at the University of Alabama at Birmingham School of Nursing

Deborah Andrews, MSHSA, RN has over 25 years of healthcare experience with a focus in nursing administration and clinical operations. Her skills include strategic planning, business development, human resource management, fiscal management, quality improvement, nursing standards, and building community relationships.

Geneva Irby, RN is BBNA vice president emeritus. She has also served as an official consultant of Traci Lynn Fashion Jewelry.

Carthenia Jefferson, RN, Esq. is an attorney and owner of Jefferson Law Firm LLC. She is also a legal nurse consultant and medical chart reviewer and was inducted as a Fellow into the American Bar Foundation in 2016.

BBNA president, Deborah Thedford-Zimmerman, MSN, RN, CWOCN is retired from the University of Alabama Birmingham Hospital where she was Bariatric Coordinator in the Transplant and Surgical Division.

Deborah Walker, MA, BSN, NE-BC is president emeritus of BBNA. She is retired from the University of Alabama Birmingham Hospital where she was Nurse Manager of Rehabilitation Nursing.

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Those on the front line of the COVID-19 crisis – medical personnel and hospital staff, law enforcement officers, and other healthcare workers – are under a tremendous amount of pressure and stress in normal circumstances that has only been amplified during the current pandemic. A study released by JAMA in March 2020 looking at the mental health outcomes of 1,257 health care workers attending to COVID-19 patients in 34 hospitals in China, where the outbreak started, found that 50% showed signs of depression, 45% reported anxiety and 72% had some form of psychological distress.

Fortunately, we have the power to change our threshold of stress. Research has shown that by harnessing our executive function skills, we can down-regulate emotional responses to stress and effectively reframe threats as opportunities. Digesting an onslaught of information, navigating dynamic high-stress environments, and employing critical reasoning skills are critical for success in any industry – but these strategic cognitive abilities are often left untrained.

In response to the impact of COVID-19 on our community, Center for BrainHealth will offer science-backed strategies and tools to help these brave men and women mitigate stress, recharge and recalibrate, and boost cognitive performance so that they can continue performing their essential jobs at an optimal level.

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- Stress Solutions
  Tactical tools for down-regulating emotional responses to stress and reframing threats as opportunities
- Sleep
  The scientific benefits of sleep, and practical strategies for achieving optimal sleep hygiene

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Six brief (2-3 minute) videos tailored to front-line healthcare providers and first responders, presenting our cognitive strategies and tools to increase brain healthy habits for stress resilience

LIVE SESSIONS:
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Members on the Move

Dr. Eric J. Williams, NBNA Immediate Past President will be the Interim Associate Dean of Health Sciences, Santa Monica College, Los Angeles.

Dr. Debra Mann co-authored an article entitled "Call to Arms: The Frontline Nurses Experience Amidst the Coronavirus Pandemic", which published in the July-September issue of the Georgia Nursing. https://www.nursingald.com/publications/2092

Dr. Debra A. Toney was a speaker at the 2020 Virtual Conference for the Infusion Nurses Society (INS). The theme of her address was "The Future of Nursing: Diversity and Inclusion". She is a member of the INS Diversity, Equity and Inclusion Task Force. Dr. Toney is a NBNA past president and the president of the National Coalition of Ethnic Minority Nurse Association.

Dr. Lindsey Harris

Dr. Lindsey Harris was installed as president of the Alabama Nurses Association on September 25, 2020. She will be the first African American president since the organization was formed in 1913! Dr. Harris is the immediate past president of the Birmingham Black Nurses Association.

Dr. Sheldon Fields, NBNA First Vice President and Chair, NBNA Health Policy Committee was featured in an article from the Binghamton University on his activism and health policy acumen. https://www.binghamton.edu/news/story/2623/nursing-and-activism-decker-alumni-fight-social-injustice

Saby St. Pierre, MSN, CCRN, published an article entitled "Advanced Care Planning: Understanding the Barriers", in the September 2020 issue of the Massachusetts Report of Nursing.

Dr. C. Alicia Georges, NBNA Past President, joined the Board of **Directors of the March of Dimes.**

Dr. C. Alicia Georges was the commencement speaker for the UCLA School of Nursing.

Dr. Stephanie Ferguson is to receive the Civitas Award from the American Academy of Nursing at its October 2020 Virtual Conference.

Dr. Millicent Gorham is to receive the Outstanding Leadership Award from the American Academy of Nursing. The award is presented to an honorary fellow of the Academy.

Michigan Governor Gretchen Whitmer of Michigan has made three appointments for Dr. Randolph Rasch, Dean, Michigan State University College of Nursing in the area of health care. In the first, **Dr. Rasch** is co-chairing, with **Dr. Audrey Gregory, RN,** CEO of Detroit Mercy, a task force to reduce maternal-infant deaths among Black Women, over represented by 44% deaths in a population that is only 14% of the overall population. Similarly, Dr. Rasch has been appointed to the Michigan Coronavirus – Racial Disparities Task Force. Finally, he has been appointed to the Michigan Department of Licensing and Regulatory Affairs (LARA) Implicit Bias Training Advisory Workgroup. Related to the latter, Dr. Rasch was invited by Governor Whitmer to participate in her press conference announcing the requirement of implicit training in the licensure renewal of a broad range of health professionals, including nurses and physicians.

In service to the profession, Dr. Rasch was recently elected as member at large of the American Association of Colleges of Nursing (AANC) Board of Directors and with him he currently serves as dean member, and board liaison of the AACN/Association of Nurse Leaders Task Force on Academic-Practice Partnerships. After serving for three years, he recently stepped down as chair of the Nursing Dean's Group of the Big Ten Academic Alliance. A Fellow in the American Association of Nurse Practitioners (FAANP) and Fellow in the National Academies of Practice (FNAP), Dr. Rasch will be inducted as a Fellow in the American Academy of Nursing (FAAN) in October, 2020.

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Chapters on the Move

Atlanta Black Nurses Association

ABNA, Inc. Members Annie-Marie Good, LaTonya Hines, Evelyn C. Miller, and Robin Simmons with the Atlanta Community Food Bank distributed food and packets of masks and hand sanitizer.

Atlanta Black Nurses Association (cont.)

ABNA, Inc. donated $250.00 each to The virtual *"Stuff the Bus"* event. The money was designated for the Atlanta Public School and Clayton County School districts for school supplies for the children.

Mary Dawson and LaTonya Hines at Georgia Congressman David Scott's Annual Health Fair.

Atlanta Black Nurses Association (cont.)

Annie-Marie Good, LaTonya Hines, Robin Simmons and Ora D. Williams, preparing packets of masks and hand sanitizer for distribution in the community.

Atlanta Black Nurses Association (cont.)

Dr. Lynn Houston-Bell, Annie-Marie Good, Pat Johnson-Gunder, Jacqueline Henson, LaTonya Hines, Evelyn C. Miller, Cynthia Moody and Robin Simmons at the Toney Valley Civic Association Free Food, Safety, and Information event.

Chapters on the Move

Western Massachusetts Black Nurses Association

Anne Mistivar, MSN, BSN, RN, LNC, is currently in school working on her DNP at Elms College. Anne is Assistant Professor with Elms College working on a grant project entitled "Haiti Initiative: Nursing Faculty Education in Haiti".

Reshunda Perry, BSN, graduated in 2018 and is now employed at the High Street Health Clinic as a Team Leader Nurse, working with one doctor and a NP, assisting five doctors during their residency

Katelyn Roberson, BSN, is a Nursing Supervisor at Bear Mountain LTC Facility in West Springfield. She is in the process of applying to the **DNP program/ FNP** to further her career in nursing.

Gabrielle Abelard, DNP, PMHNP, PMHCNS-BC, RN, BS, was selected by the Board of the American Psychiatric Nurses Association (APNA) New England chapter as this year's recipient of the **Nancy M. Valentine Excellence in Leadership Award**. Dr. Abelard is a Clinical Assistant Professor, University of Massachusetts, Amherst https://www.umass.edu/nursing/news-events/news/gabrielle-abelard-receive-npna-excellence-leadership-award.

Khadijah Tuitt, DNP, PMHNP-BC, recently completed the DNP program (from which university and when). She is co-chairing the Anti-Racism Task Force for Baystate Health. Dr. Tuitt was featured on a podcast. https://anchor.fm/steven-opalenik/episodes/Episode-35-Welcome-To-The-Village---Dr--Khadijah-Tuitt-ei8adq

Veronica W Barrett, MSN, MA Ed Psych, RN, HNB-BC, has been a nurse for over 30 years. She is the Western MA Regional School Nurse Consultant. As a founding member of the Western MA Black Nurses Association, Veronica is grateful to all the nurses who sustained and nurtured the WM chapter. She is excited to be rejoining this group as a lifetime member.

South Eastern Pennsylvania Black Nurses Association

Tiffany E Gibson, MSN, NPD-BC, CPN, GHDL, is a recipient of the NBNA under 40 Award for 2020.

Heather Lawson, MSN, NP-C and **Eula Davis, MPH, MSN, RN-BC,** crafted a letter in support of the Nurses on Boards Coalition initiative to have 10,000 nurse on boards by the end of this year.

Monica Harmon, MSN, MPH, RN, President of SEPA-BNA was appointed to the Dean's Advisory Council of Nursing and Health Professions at Drexel University.

Keyanna Bynum (Student) member was inducted into Sigma Theta Tau International. Keyanna has started her own candle business. @ bynumcandle.com

Eula Davis, MPH, MSN, RN-BC, made a poster presentation at the VA Clinic in Philadelphia to help veterans understand what services the Rheumatology Clinic provides and how to access services.

Eula Davis, MPH, MSN, RN-BC, conducted a poster presentation at the VA Clinic after receiving a grant from the State of Pennsylvania for the Walk with Ease Program. This program offers to veterans information about arthritis and ways to decrease symptoms.

Olive Massaquoi, nursing student member, received The Route Beauty Scholarship for $1000 from NBNA. She attends the Delaware County Community College.

Chapters on the Move

Birmingham Black Nurses Association

On June 8, BBNA members Myra Moore and Tanisha Leonard participated in the Community Health Forum sponsored by Brenda's Brown Bosom Buddies, an organization that supports women/men of color who are either breast cancer survivors or have been directly affected by the disease. The virtual forum was held on FaceBook Live. Ms. Moore shared information about breast cancer diagnosis, surgery, treatment, and recovery. Ms. Leonard presented health information about diabetes and its management. After the presentations, presenters answered questions from the audience.

Dr. Marcia Lowe's manuscript entitled "An Exploratory Study of the Influence of Perceived Organizational Support, Coworker Social Support, the Nursing Practice Environment, and Nurse Demographics on Burnout in Palliative Care Nurses" has been accepted for publication in the December 2020 issue of *The Journal of Hospice and Palliative Nursing.* This is Dr. Lowe's dissertation topic.

BBNA Nurse of the Year awardees include: Dr. Loretta Lee-Nurse Educator of the Year; Alean Nash-Staff Nurse of the Year; Fannie Jones-Uniformed Services Nurse of the Year; Taylor Washington-40 and Under Awardee.

Melanie Wren was selected for the Suncrest Hospice Scholarship award by NBNA. Melanie is a student in the Ida Moffett School of Nursing at Samford University. She is the student representative on the BBNA Board of Directors.

On July 30, BBNA member, Attorney Carthenia Jefferson was a panelist on a virtual community program. The title of the program was "Advocating for a Declaration of Racism as Public Health Crisis." Panelists included physicians, nurses, public health professionals, community organizations, and business owners.

July 31, BBNA participated in a food drive and book giveaway with The Core of Christ Church in Fairfield, AL. Food boxes and children's books were prepared for 400 cars.

Chapter Presidents

ALABAMA

Birmingham BNA (11)	Deborah Thedford-Zimmerman	Birmingham, AL
Montgomery BNA (125)	Katherine Means	Montgomery, AL
Northern Alabama BNA (180)	Bridgette Taylor	Harvest, AL
Tuskegee/East Alabama NBNA (177)	Dr. Cordelia Nnedu	Tuskegee Institute, AL
West Alabama Chapter of the NBNA (184)	Dr. Johnny Tice	Tuscaloosa, AL

ARIZONA

BNA Greater Phoenix Area (77)	LaTanya Mathis	Phoenix, AZ

ARKANSAS

Little Rock BNA of Arkansas (126)	Jason Williams	Little Rock, AR

CALIFORNIA

Bay Area BNA (02)	Norma Faris-Taylor	Oakland, CA
Capitol City BNA (162)	Carter Todd	Sacramento, CA
Central Valley BNA (150)	Dr. Jeanette Moore	Fresno, CA
Council of Black Nurses, Los Angeles (01)	Barbara Collier	Los Angeles, CA
Greater Inland Empire BNA (188)	Nia M. Martin	Corona, CA
San Diego BNA (03)	Samantha Gambles Farr	San Diego, CA

COLORADO

Eastern Colorado Council of BN (Denver) (127)	Robin Bruce	Denver, CO

CONNECTICUT

Northern Connecticut BNA (84)	Marlene D. Harris	Hartford, CT
Southern Connecticut BNA (36)	Andrea Murrell	West Haven, CT

DISTRICT OF COLUMBIA

BNA of Greater Washington, DC Area (04)	Dr. Pier Broadnax	Washington, DC

FLORIDA

Big Bend BNA (Tallahassee) (86)	Katrina Rivers	Tallahassee, FL
BNA, Tampa Bay (106)	Rosa Cambridge	Tampa, FL
Central Florida BNA (35)	Eloise Abrahams	Orlando, FL
First Coast BNA (Jacksonville) (103)	Dr. Carol Jenkins-Neil	Jacksonville, FL
Greater Fort Lauderdale Broward Chapter of the NBNA (145)	Lyn Peugeot	Fort Lauderdale, FL
Greater Gainesville BNA (85)	Voncea Brusha	Gainesville, FL
Miami Chapter - BNA (07)	Patrise Tyson	Miami, FL
Palm Beach County BNA (114)	Rochun McCray	West Palm Beach, FL
St. Petersburg BNA (28)	Janie Johnson	St. Petersburg, FL
Treasure Coast Council of BN (161)	Dr. Ophelia McDaniels	Port Saint Lucie, FL
Volusia Flagler Putnam Chapter of the NBNA (187)	Dr. Alma Dixon	Palm Coast, FL

Chapter Presidents

GEORGIA

Atlanta BNA (08)	Seara McGarity	College Park, GA
Columbus Metro BNA (51)	Pamela Rainey	Columbus, GA
Concerned National BN of Central Savannah River Area (123)	Romona Johnson	Martinez, GA
Middle Georgia BNA (153)	Dr. Debra Mann	Dublin, GA
Okefenokee BNA (148)	Connie Bussey	Waycross, GA
Savannah BNA (64)	Yvonne Bradshaw	Savannah, GA

HAWAII

Honolulu BNA (80)	Linda Mitchell	Aiea, HI

ILLINOIS

Alliance of BNA of Illinois (178)	Beatrice Mbaocha	Chicago, IL
BNA of Central Illinois (143)	Dr. Elaine Hardy	Bloomington, IL
Chicago Chapter NBNA (09)	Ellen Durant	Chicago, IL
Greater Illinois BNA (147)	Patricia Roberts	Bolingbrook IL
Illinois South Suburban NBNA (168)	Dr. Carol Alexander	Matteson, IL
North Shore BNA (172)	Linda Spriggs	Gurnee, IL

INDIANA

BNA of Indianapolis (46)	Katherine Bates	Indianapolis, IN
Lake County Indiana BNA (169)	Michelle Moore	Merrillville, IN
Northwest Indiana BNA (110)	Mona Steele	Gary, IN

KANSAS

Wichita BNA (104)	Linda Wright	Wichita, KS

KENTUCKY

KYANNA BNA, Louisville (33)	Alona Pack	Louisville, KY
Lexington Chapter of the NBNA (134)	Dr. Lovoria Williams	Lexington, KY

LOUISIANA

Acadiana BNA (131)	Iris Malone	Lafayette, LA
Bayou Region BNA (140)	Salina James	Thibodaux, LA
New Orleans BNA (52)	Mary Kelly	New Orleans, LA
Shreveport BNA (22)	Bertresea Evans	Shreveport, LA
Southeastern Louisiana BNA (174)	Rachel Weary	Abita Springs, LA

MARYLAND

BNA of Baltimore (05)	Dr. Vaple Robinson	Baltimore, MD
BN of Southern Maryland (137)	Kim Cartwright	Clinton, MD
Greater Bowie Maryland NBNA (166)	Dr. Jacqueline Newsome-Williams	Chevy Chase, MD

MASSACHUSETTS

New England Regional BNA (45)	Sasha DuBois	Roxbury, MA
Western Massachusetts BNA (40)	Anne Mistivar-Payen	Springfield, MA

Chapter Presidents

MICHIGAN

Detroit BNA (13)	Nettie Riddick	Detroit MI
Grand Rapids BNA (93)	Aundrea Robinson	Grand Rapids, MI
Greater Flint BNA (70)	Juanita Wells	Flint, MI
Kalamazoo-Muskegon BNA (96)	Dr. Birthale Archie	Kentwood, MI
Lansing Area BNA (149)	Meseret Hailu	Lansing, MI
Southwest Michigan BNA (175)	Deborah Spates	Berrien Springs, MI

MINNESOTA

Minnesota BNA (111)	Sara Wiggins	St. Paul, MN

MISSOURI

BNA of Greater St. Louis (144)	Quita Stephens	St. Louis, MO
Greater Kansas City BNA (74)	Iris Culbert	Kansas City, MO
Mid-Missouri BNA (171)	Felicia Anunoby	Jefferson City, MO

NEBRASKA

Omaha BNA (73)	Shanda Ross	Omaha, NE

NEVADA

Southern Nevada BNA (81)	Lauren Edgar	Las Vegas, NV

NEW JERSEY

Concerned BN of Central New Jersey (61)	Terri Ivory	Neptune, NJ
Concerned Black Nurses of Newark (24)	Banita Herndon	Newark, NJ
Mid State BNA of New Jersey (90)	Tracy Smith-Tinson	Somerset, NJ
Middlesex Regional BNA (136)	Marchelle Boyd	New Brunswick, NJ
New Jersey Integrated BNA (157)	Thomas Hill	Lyons, NJ
Northern New Jersey BNA (57)	Dr. Melissa Richardson	Newark, NJ

NEW YORK

Greater New York City BNA (167)	Dr. Julius Johnson	Brooklyn, NY
New York BNA (14)	Dr. Rose Ellington-Murray	New York, NY
Rochester BNA (182)	Dr. Yvette Conyers	Rochester, NY
Suffolk County BNA (183)	Jacqueline Winston	Ridge, NY

NORTH CAROLINA

Central Carolina BN Council (53)	Bertha Williams	Durham, NC
Piedmont BNA (181)	Tammy Woods	Charlotte, NC

OHIO

Akron BNA (16)	Deandreia Mayes	Akron, OH
BNA of Greater Cincinnati (18)	Dr. Regina Hutchins	Cincinnati, OH
Central Ohio BNA (185)	LaToya Gibson	Columbus, OH
Cleveland Council BNA (17)	Dr. LaTonya Martin	Cleveland, OH
Columbus BNA (82)	Pauline Zarrieff	Columbus, OH
Youngstown Warren BNA (67)	Carol Smith	Youngstown, OH

Chapter Presidents

OKLAHOMA

Eastern Oklahoma BNA (129)	Rickesha Clark	Tulsa, OK
Oklahoma City BNA (173)	Irene Phillips	Jones, OK

OREGON

Alliance of BNA of Oregon (186)	Danaya Hall	Portland, OR

PENNSYLVANIA

Pittsburgh BN in Action (31)	Dr. Dawndra Jones	Pittsburgh, PA
Southeastern Pennsylvania Area BNA (56)	Monica Harmon	Philadelphia, PA

SOUTH CAROLINA

Columbia Area BNA (164)	Whakeela James	Columbia, SC
Midlands of South Carolina BNA (179)	Lisa Davis	Columbia, SC
Tri-County BNA of Charleston (27)	Vivian Frasier-Gathers	Charleston, SC

TENNESSEE

Memphis-Riverbluff BNA (49)	Betty Miller	Memphis, TN
Nashville BNA (113)	Shawanda Clay	Nashville, TN

TEXAS

BNA of Austin (151)	Janet VanBrakle	Austin, TX
BNA of Greater Houston (19)	Cynthia Brown	Houston, TX
Central Texas BNA (163)	Mack Parker	Temple, TX
Fort Bend County BNA (107)	Marilyn Johnson	Pearland, TX
Galveston County Gulf Coast BNA (91)	Leon McGrew	Galveston, TX
Greater East Texas BNA (34)	Melody Hopkins	Tyler, TX
Metroplex BNA (Dallas) (102)	Dr. Becky Small	Dallas, TX
Southeast Texas BNA (109)	Stephanie Williams	Port Arthur, TX

VIRGINIA

BNA of Charlottesville (29)	David Simmons, Jr.	Charlottesville, VA
Central Virginia Chapter of the NBNA (130)	Dr. Tamara Broadnax	North Chesterfield, VA
NBNA: Northern Virginia Chapter (115)	Joan Pierre	Woodbridge, VA

WISCONSIN

Milwaukee BNA (21)	Karina Brown	Milwaukee, WI
Racine-Kenosha BNA (50)	Joyce Wadlington	Racine, WI

Direct Member (55)*

*Only if there Is no Chapter in your area