Sickle Cell Today

VOL. 21, ISSUE 1
MARCH 2024

USA HEALTH
JOHNSON HAYNES JR., M.D.
COMPREHENSIVE SICKLE CELL CENTER

Table of Contents

June 19
World
Sickle Cell Day

Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center
Main office
251-470-5893
251-470-5895 fax

Clinical research
251-471-7703

Pediatric clinic
251-405-5147

Adult clinic
251-470-5890

Community-based program
251-432-0301

Transition coordinator
251-470-5875

On the Cusp of a Cure

Felicia L. Wilson, M.D., FAAP
USA Health Department of Hematology/Oncology

In a landmark decision on Dec. 8, 2023, the Food and Drug Administration (FDA) approved Casgevy and Lyfgenia as the first gene therapies for treatment that can potentially cure sickle cell disease (SCD). Casgevy, the first FDA-approved treatment utilizing a type of gene-editing technology called CRISPR/Cas9, marks a major advance for treating SCD and other diseases like cancer, diabetes and Alzheimer's.

Until now, the only approved curative therapy was hematopoietic stem cell transplant, including bone marrow transplant, umbilical cord blood transplant, and peripheral blood transplant, which involves replacing abnormal stem cells in bone marrow with healthy stem cells from a donor who matches your tissue type. They are most effective in children who have well-matched donors. Unfortunately, HSCT is not widely available because most patients with SCD, up to 80%, do not have a suitable donor.

Gene therapy does not require a donor. Most adults cannot tolerate the toxicities of HSCT, which can be significant and occasionally fatal due to the chemotherapy required to wipe out the sickle HSCs.

Casgevy and Lyfgenia are approved for people ages 12 years and older with hemoglobin SS and S-beta zero thalassemia who do not have recurring viral infection or significant organ damage. A donor is not required because both products are made from the patient's own blood stem cells, which are modified and given back as a one-time, single-dose infusion.

Once the bone marrow HSCs are collected, they are taken to a lab. While the stem cells are being edited, chemotherapy is given to remove the sickle HSCs and make space for the billions of newly-edited cells to be infused.

The most common side effects were low levels of platelets and white blood cells, mouth sores, nausea, musculoskeletal pain, abdominal pain, vomiting, fever, low white blood cell count, headache and itching. Patients who received Casgevy or Lyfgenia will be followed in a long-term study to evaluate each product's safety and effectiveness.

> This is a milestone to celebrate in sickle cell treatment and the rapidly advancing field of gene editing.

Though the procedure is the same, the gene therapies are scientifically different. Casgevy utilizes CRISPR/Cas9, which can cut DNA in targeted areas, enabling the ability to accurately edit where it was cut. Casgevy edits the BCL11A gene, which tells the body to make less fetal and more adult hemoglobin. The modified HSCs are given back to the patient, where they attach and multiply within the bone marrow and increase the production of fetal hemoglobin (HbF), which facilitates oxygen delivery. Increased levels of HbF prevent the sickling of red blood cells.

Casgevy's safety and effectiveness were evaluated in an ongoing single-arm, multi-center trial in adult and adolescent patients. Of the 31 patients with sufficient follow-up time to be evaluable, 29 (93.5%) achieved freedom from severe VOCs episodes for at least 12 consecutive months during the 24-month follow-up

continued...

period. All treated patients achieved successful engraftment, with no patients experiencing graft failure or graft rejection.

Lyfgenia is a cell-based gene therapy that uses a harmless virus to insert a gene into a patient's stem cells. They are genetically modified to produce HbAT87Q, a gene-therapy-derived hemoglobin that functions similarly to normal hemoglobin A, the normal adult hemoglobin. Red blood cells containing HbAT87Q have a lower risk of sickling and occluding blood flow. These modified stem cells are then delivered to the patient.

Lyfgenia was studied in two clinical trials, tracking the treatment's effectiveness and side effects for as long as five years. Among 34 evaluable patients, no VOCs occurred between six and 18 months after infusion in 88% of patients, and no severe VOCs in 94%. The study participants had experienced a median of three severe VOCs per year in the two years leading up to the trial.

Researchers tracked anti-sickling hemoglobin levels in patients, with median levels hovering close to normal as of last study visits. Hematologic malignancy (blood cancer) has occurred in two patients treated with Lyfgenia. A black box warning is included regarding this risk and should be monitored.

Approval of the first gene therapies for SCD represents a tremendous step forward. They are potentially life-changing, but expensive. Casgevy will cost $2.2 million, while Lyfgenia is $3.1 million. The companies say they are working with private and public insurers. Advocates note the price could be offset by the savings in lifetime care of sickle cell complications.

Though a milestone, everyone is not yet eligible, and long-term data on the effectiveness and safety is needed. Still unmet needs require continued research into a variety of treatment options beyond gene therapy.

Gene therapy is not without risks, but this is a milestone to celebrate in sickle cell treatment and the rapidly advancing field of gene editing.

To learn more about Vertex's Casgevy, visit casgevy.com. To learn more about bluebird bio's Lyfgenia, visit mybluebirdsupport.com.

Optimizing Disease Modifying Therapies in Children with Sickle Cell Disease

Mikayla Johnson, PA-C, and Preethi Marri, M.D.
USA Health Division of Pediatric Hematology/Oncology

Exceptional progress has been made in understanding the complex pathophysiology of SCD. After nearly a century, multiple new and exciting disease-modifying therapies have emerged. But until gene therapy is approved and more readily available, these disease-modifying therapies should be optimized to allow patients with SCD to live full, disease-free lives.

Until the 1980s, red blood cell transfusions were the only routine disease-modifying therapy.[1] Today, there are four widely used, FDA-approved disease-modifying agents available for management of SCD.

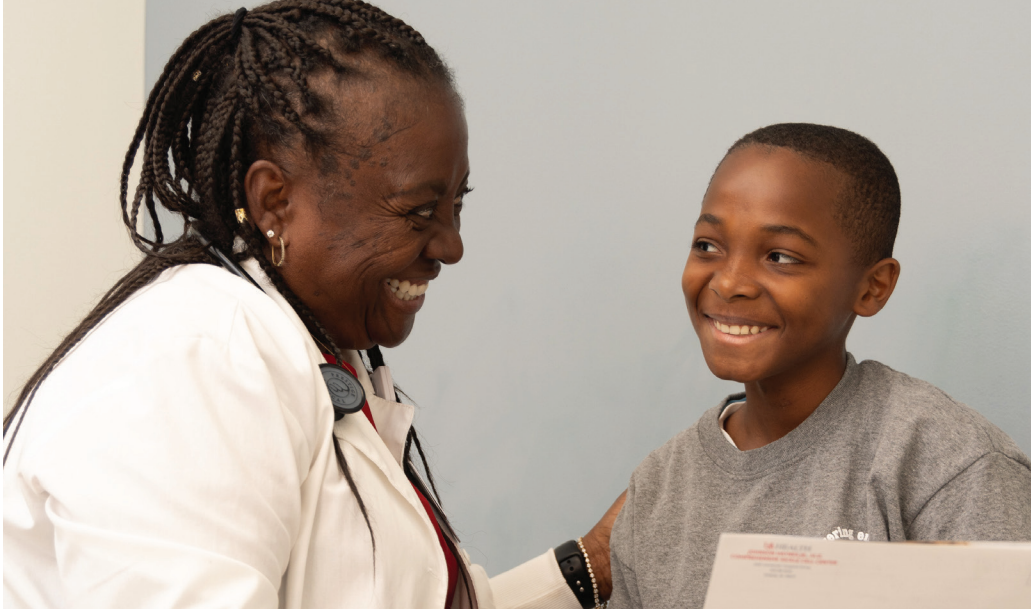
Hydroxyurea (HU), the oldest and most used, is effective in increasing fetal hemoglobin (HbF). The increase inhibits the intracellular polymerization of hemoglobin S (HbS), which prevents red blood cells from sickling, lowers their destruction, and reduces adhesion vessel endothelium.[2] Approved for adults in 1998 and children in 2017, it decreases pain crises, incidence of acute chest syndrome (ACS), and need for blood transfusions by about 50%.[1] Clinical trials have shown it to be safe and effective for SCD patients as young as 6 months old. Available in tablet and liquid forms, HU can cause dry skin (in infants and children), rashes, neutropenia, and headaches.

L-Glutamine, or Endari,® is a disease-modifying agent that causes an excess of glutamine in blood vessels. Sickle-shaped cells then take it up and form neutralizing antioxidant molecules, which limit destruction of cells and reduce turbulence in blood vessels. In a phase 3 clinical trial, Endari® led to fewer hospitalizations, VOC, and incidence of ACS over a 48-week period compared to patients receiving a placebo.[4] FDA-approved in 2017, Endari® can cause chest pain, headache, flatulence, constipation, nausea, abdominal pain, myalgias, and cough.[2]

Adakveo® is a monoclonal antibody that binds to P-selectin and consequently inhibits the adherence of RBCs to vessel endothelium. It's praised for its ability to decrease VOCs. In a study, the Adakveo® group reported 50% less VOC episodes and a 3-month longer time-to-first VOC compared to the placebo group.[5] Approved in 2019 as a monthly IV infusion for patients 16 years and older, Adakveo® can cause abdominal pain, nausea, arthralgias, back pain, infusion reactions, and fever.

Voxeletor, or Oxbryta®, is an HbS polymerization inhibitor that binds to hemoglobin and stabilizes its oxygenated state. Trials have found it improves erythrocyte deformability, blood-cell-oxygen-carrying capacity, oxygen delivery to tissues, and decreases blood viscosity. Others report remission of jaundice, significant improvement of overall quality of life, rise in Hb >1g/dL from baseline, increased oxygen saturation, reduced markers of hemolysis, and decreased need for hospital admission for VOC pain crises in several patients within 24 weeks of starting the medication.[3] For patients taking hydroxyurea, it can help achieve a higher hemoglobin concentration. FDA-approved in 2019, this oral tablet prescribed to patients 4 years and older can cause abdominal pain, diarrhea, headache, fever, nausea, and skin rash.

1. McGann, Patrick T, and Russell E Ware. "Hydroxyurea Therapy for Sickle Cell Anemia". Expert Opinion on Drug Safety, U.S. National Library of Medicine, 2015, www.ncbi.nlm.nih.gov/pmc/articles/PMC5868345/.
2. Lexicomp Online. Lexi-Drugs/"Hydroxyurea"/"Endari". UpToDate, Inc; 2023. Accessed October 24, 2023
3. AlDallal, Salma M. "Voxelotor: A Ray of Hope for Sickle Disease." Cureus, U.S. National Library of Medicine, 26 Feb. 2020, www.ncbi.nlm.nih.gov/pmc/articles/PMC7100618/.
4. Elenga, Narcisse, et al. "Real-World Data on Efficacy of L-Glutamine in Preventing Sickle Cell Disease-Related Complications in Pediatric and Adult Patients." Frontiers in Medicine, U.S. National Library of Medicine, 1 Aug. 2022, www.ncbi.nlm.nih.gov/pmc/articles/PMC9376442/.
5. Kutlar, Abdullah. "Effect of Crizanlizumab on Pain Crises in ... - Wiley Online Library." Wiley Online Library, Jan. 2019, onlinelibrary.wiley.com/doi/10.1002/ajh.25308.



Sickle Cell Disease Management and Treatment: Barriers and Challenges for Caregivers

Ardie Pack-Mabien, Ph.D., FNP-BC

Sickle cell disease (SCD), an autosomal recessive hematological disorder, is the result of single gene mutation that involves the substitution of valine for glutamic acid in the sixth position of chromosome 11 of the beta globin gene. It affects approximately 100,000 individuals in the United States.[1,2] This hematological disorder is associated with sickling of erythrocytes and is characterized by chronic inflammation, multicellular mediated vascular occlusion, hemolytic anemia, recurrent and intermittent vaso-occlusive pain episodes, and end organ damage that is life-long and potentially fatal.[3, 2] There are currently four FDA-approved therapies for the management and treatment of sickle cell disease. These therapies include Hydroxyurea, Endari, Adakveo, and Oxbryta.

Despite evidence-based data and recommendations by policymakers (American Society of Hematology, Centers for Disease Control and Prevention, and National Institute of Health) on the potential benefits of disease-modifying therapies, they are underutilized. Caregivers of children with SCD want more information about them, their side effects, and insurance requirements that may prevent or limit access to care.[4,5] They face multiple challenges, altered family dynamics, and time-consuming demands of everyday living, as well as emotional and psychosocial stressors, and financial constraints that can affect their ability to support their child or children with SCD.[6,7,8]

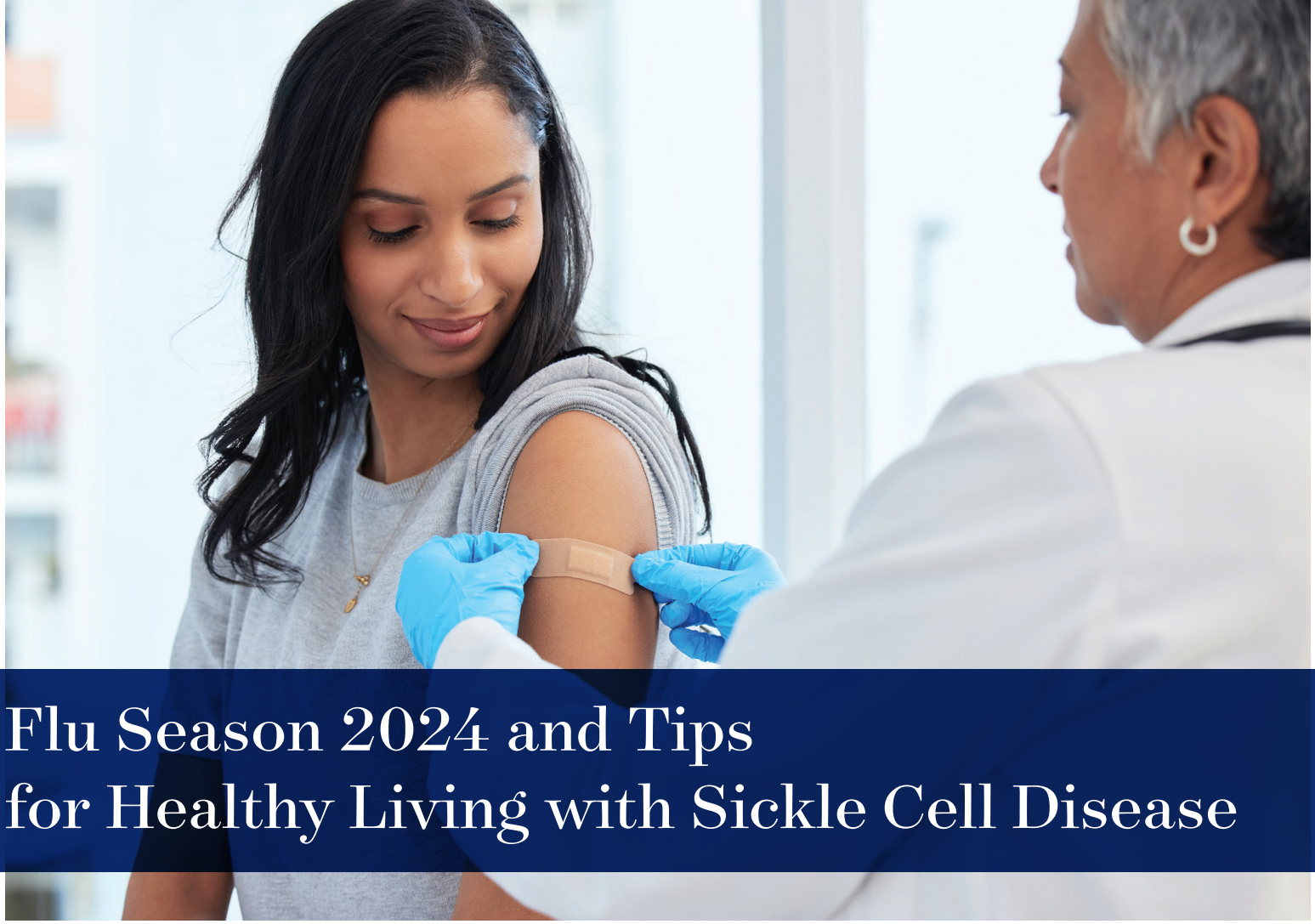
Caregivers experience societal challenges, such as stigma, discrimination and prejudice. They may navigate their own chronic health issues, managing the logistics of medical appointments for themselves and their child.[9, 8] In a cross-sectional study of caregivers of children with SCD (n = 63), 26% had chronic disease (diabetes, hypertension, SCD), and 35% took medication daily and had at least one hospital admission in a 6-month period.[8] Of note, the study found emotions, sleep quality, and sexual life were most affected, with negativity exceeding positivity.[8]

Clinical and nonclinical factors also may impede access to care and transition services. These risk factors include: a) hemoglobinopathy status with markers of milder disease to severe; b) travel distance to the clinic > 30 miles; and c) age greater than 21 years at the time of beginning the transition process.[10]

Healthcare providers can take steps to address these barriers and challenges.

- Understand everyone—case management, behavioral health, mental health, school nurse, healthcare provider, and caregiver—assists in prevention and/or increases adherence.
- Consider actions to increase utilization and adherence with disease-modifying therapy use among children with sickle cell anemia.
- Track follow-up on those actions in electronic health records.
- Consult case management, social worker, behavioral and mental health, or local community-based organizations, such as the Sickle Cell Disease Association of America.
- Integrate screening appointments, such as ophthalmology and TCD into a single, comprehensive sickle cell visit when possible.
- Include caregivers when scheduling appointments.
- Educate caregivers about annual diagnostic screening.
- Develop and promote peer support and focus groups.
- Consolidate pediatric and adult care within the same medical home.
- Develop patient and provider resources to improve understanding disease-modifying therapies and the importance of annual TCD screening to prevent childhood stroke.
- Connect patients and families with resources and tools to schedule screening appointments and support transportation needs by identifying financial assistance.
- Address practice barriers, such as lack of support staff or time, to provide hydroxyurea counseling.
- Incorporate reminders into the electronic health record.
- Develop tools to help patients take medication as directed, such as reminder apps on mobile devices.[11, 12, 9]

References:
1. Ballas, S. K. (2015). Pathophysiology and principles of management of the many faces of the acute vaso-occlusive crisis in patients with sickle cell disease. European Journal of Haematology, 95(2), 113-123. https://doi:10.1111/ejh.12460
2. Thein, M. S., Igbineweka, N. E., & Thein, S. L. (2017). Sickle cell disease in the older adult. Pathology, 49(1), 1-9. https://doi:10.1016/j.pathol.2016.10.002
3. Cancio, M. I., Helton, K. J., Schreiber, J. E., Smeltzer, M. P., Kang, G., & Wang, W. C. (2015). Silent cerebral infarcts in very young children with sickle cell anaemia are associated with a higher risk of stroke. British Journal of Haematology, 171(1), 120-129. https://doi: 10.1111/bjh.135
4. Newman, T., Yang, J., Suh, K., Jonassaint, C., Kane-Gill, S., & Novelli, E. (2022). Trends of disease modifying treatment use in sickle cell disease: Retrospective analysis of claims data, 2014-2020. Blood, 140(Supplement 1). 1389-1390. 64th ASH Annual Meeting Abstract. https://doi.org/10.1182/blood-2022-159197
5. Kazarow, C., Novelli, E.M., Kane-Gill, S., Jonassaint, C.L., Jalowsky, M., Lewis, C.A., & Newan, T. (2022). Barriers to the use of disease modifying treatments in SCD: A survey of patients and caregivers. Blood, 140(Supplement 1). 5152-5153. 64th ASH Annual Meeting Abstract. https://doi.org/10.1182/blood-2022-170881
6. Ali, R., & Razeq, N. (2017). The lived experience of parents of children with sickle cell disease: A qualitative study. Open Journal of Nursing, 7, 1348-1364.
7. Karadag, G., Gungormus, Z., & Olcar, Z. (2018). Experiences and problems encountered by families of children with sickle cell anemia. Journal of Caring Sciences, 7(3), 125-129. http://doi.10.1517/jcs.2018.0202.
8. Madari, B.M., Raddadi, R.A., Japino, S.A., Omer, M., & Al Awa, M. (2018). Quality of life among caregivers of sickle cell disease patients: A cross-sectional study. Health and Quality of Life Outcomes, 16(176), 1-9. https://doi.org/10.1186/s12955-018-1009-5
9. Caz, Robin (2019). My baby has sickle cell disease. Support and guidance for parents raising a child with SCD. ISBN 978-1-7016-1188-7
10. Andemariam, B., Owarish-Gross, J., Grady, J., Boruchov, D., Thrall, R. S., & Hagstrom, J. N. (2014). Identification of risk factors for an unsuccessful transition from pediatric to adult sickle cell disease care. Pediatric Blood & Cancer, 61(4), 697-701. https://doi: 10.1002/pbc.24870
11. Platt, A., Eckman, J., & Hus, L. (2011). Revised 3rd ed. Hope and Destiny. The patient and parent's guide to sickle cell disease and sickle cell trait. Hilton Publishing Company.
12. Platt, A. & Sacerdote, A. (2002). Hope and Destiny. A patient's and parent's guide to sickle cell disease and sickle cell trait.



Flu Season 2024 and Tips for Healthy Living with Sickle Cell Disease

Jessica King, FNP-BC

The flu is a contagious respiratory illness caused by influenza viruses that can infect the nose, throat and lungs. Catching the flu often leads to missed days from work and school every year.

The flu also can cause individuals infected to develop serious health complications that can be life-threatening and result in death. Since the flu can cause serious and even fatal illnesses, it is important to obtain the annual flu vaccine as a preventative measure. This is especially true for individuals who are at increased risk for flu complications, such as pregnant women, children younger than 5 years, people ages 65 years and older, and individuals living with chronic medical illnesses such as asthma, diabetes, heart disease, and sickle cell disease.

In the United States, the flu season classically begins in the month of October, peaks between December and February, and levels off around April and May. Consequently, scientists and researchers monitor and review the data collected the previous year to match the flu vaccination to the most common flu viruses that are most likely to circulate annually.

The 2023–24 annual influenza vaccines provide coverage for Influenza A (H1N1/A Victoria and H3N2/A Darwin) and Influenza B (B/Victoria and B/Yamagata).

The CDC recommends that all individuals ages 6 months and older, unless contraindicated, should obtain their annual flu vaccine as a measure of prevention. Since it takes two weeks for antibodies from a vaccine to develop, recommendations are that individuals obtain their annual flu vaccine in September, prior to the onset of the season.

If you were unable to obtain the flu vaccine between September and October, it is still recommended to obtain the vaccine throughout the season, which continues until May. To obtain your vaccine, please contact your primary care provider, hematologist, or sickle cell specialist. You also can obtain the flu vaccine at your local pharmacy based on availability.

In efforts to assist you and your families with maintaining optimal health and wellness this season, the CDC recommends the following tips:

- Proper hand washing with soap and water for 20 seconds.
- If handwashing is not an option, applying hand sanitizer to hands and rubbing for at least 30 seconds.
- Routinely cleaning commonly touched surfaces, such as door handles, cell phones, light switches, toys, remote controls, etc., with disinfectants.
- Avoid touching your face with your hands.
- Avoid sharing food or drinks, shaking hands, and close contact with others such as kissing or hugging.
- Turn your head and cough, or sneeze into a napkin or the sleeve of your elbow.
- Stay home if you are sick.
- Contact your healthcare provider for flu-like symptoms, such as fever, cough, chest pain, shortness of breath, headache, body aches, vomiting, and diarrhea.
- Contact your healthcare provider to schedule your annual flu vaccine, find out about testing, and recommended treatments.

For additional information regarding the flu virus, spread, prevention, and vaccination, visit the Centers for Disease Control and Prevention website at www.cdc.gov/flu/season/faq-flu-season-2023-2024.htm

Since the flu and other common illnesses, such as COVID-19 and Respiratory Syncytial Virus (RSV), can quickly become serious for someone living with sickle cell disease (SCD), the best defense is to have a good offense. Listed below are some tips from the CDC website for healthy living with SCD.

- Wash your hands before preparing your food and eating, and after going to the bathroom, blowing your nose, coughing, sneezing, shaking hands, or touching people or things that carry germs, such as diapers, uncooked food, (e.g. raw meat, raw eggs, and unwashed vegetables), animals, or trash.
- Utilize good food safety rules, such as washing hands, cutting boards, counters, and utensils after they have touched uncooked foods.
- Wash vegetables and fruits well prior to eating.
- Cook meat until it is well done.
- Do not eat raw eggs.
- Avoid reptiles, such as lizards, snakes, and turtles.
- Stay up to date with all recommended immunizations, including the COVID-19 booster, as suggested by the CDC.
- Take medications as prescribed by your healthcare provider.
- Get regular health checkups.
- Drink 8-10 eight-ounce glasses of water per day.
- Dress appropriately for the weather.
- Stay active, but be careful not to overdo it. Rest when tired, and drink plenty of water.
- Find a good patient support group by getting involved with a local community-based organizations, such as the Sickle Cell Disease Association chapter in your area, which can provide information, assistance, and support.

For additional information and healthy living tips for individuals living with SCD, you may visit the Centers for Disease Control and Prevention website at www.cdc.gov/ncbddd/sicklecell/documents/tipsheets_living.pdf

Centers for Disease Control and Prevention. (2023, November 15). Sickle cell disease tips for healthy living: 5 tips to help prevent infection. www.cdc.gov/ncbddd/sicklecell/documents/tipsheets_living.pdf

Centers for Disease Control and Prevention. (2023, November 15). Sickle cell disease tips for healthy living: Living well with sickle cell disease. www.cdc.gov/ncbddd/sicklecell/healthyliving-living-well.html

Centers for Disease Control and Prevention, national center for immunization and respiratory diseases . (2023, October 24). Information for the 2023-2024 Flu Season. www.cdc.gov/flu/season/faq-flu-season-2023-2024.htm

Sickle Cell Center, Community Still Mourn Haynes' Passing, Yet His Legacy Provides Motivation

The Johnson Haynes Jr., M.D., Comprehensive Sickle Cell Center honors its namesake's dedication to treating patients, and for the providers who worked alongside him, it's a reminder of the legacy they feel called to live up to.

"The unexpected and untimely passing of Dr. Johnson Haynes, Jr., has been very hard," said Ardie Pack-Mabien, Ph.D., FNP-BC, director of the center. "The sickle cell center staff, community, and many of our patients are still trying to deal with his loss."

> **"He was an amazing teacher and an even better man. Over the years, Dr. Haynes was not only my mentor, but he became a dear friend and a father-like figure."**
>
> *- Antwan Hogue, M.D.*

Haynes committed more than 20 years to caring for most of the adults with sickle cell disease in the southern half of Alabama.

"As the collaborating physician for the Johnson Haynes, Jr., M.D., Comprehensive Sickle Cell Center, I understand that I have giant shoes to fill," Antwan Hogue, M.D., senior hospitalist, associate professor at the Whiddon College of Medicine, and the center's medical director, said. "His team respected him, and his patients adored him. He is greatly missed."

Providers are still inspired by how he cared and advocated for his patients.

"I knew Dr. Haynes as one of the most caring providers for patients with sickle cell disease," said Hamayun Imran, M.D., M.Sc., division chief of pediatric hematology and oncology at Children's & Women's Hospital and professor of pediatrics. "He cared about healthcare disparities and advocated for responsible treatment of opioids for those suffering from pain."

Haynes' impression extended beyond the clinical setting. Hogue still remembers meeting him in 2006 as an undergraduate student at the University of South Alabama.

"He was an amazing teacher and an even better man. Over the years, Dr. Haynes was not only my mentor, but he became a dear friend and a father-like figure," he said. "He was and will always be a legend to me. He helped me through some difficult times, and I will always appreciate him for that."

Strategies to Promote Overall Well-Being for Caregivers

Caring for a child or family member with a chronic illness, such as sickle cell disease (SCD), can be emotionally and physically challenging. It is crucial for caregivers to adopt coping strategies that promote overall well-being for the family. Here are some strategies:

Jasmeka Foster, M.S.; Katey Hayes, M.S.; Jasmin Pizer, M.S. | University of South Alabama Psychology Department

For Caregivers of Children and Adults:

- **Educate Yourself:** Learn as much as you can about the chronic illness, and don't be afraid to ask questions during medical care visits. Understanding and knowledge of SCD will help you better care for your loved one, make informed decisions, and increase shared decision making.
- **Build a Support Network:** Connect with other caregivers who are going through similar experiences. Support groups and online communities can provide emotional support and valuable information. Ask for help from friends and family during difficult times. Give yourself a break from caregiving to engage in pleasurable activities (e.g., hobbies, walking, talking to a friend), which are essential to help prevent burnout!
- **Routine and Planning:** Create a structured daily schedule to manage medication, appointments, and treatments. Planning ahead can reduce the stress and worry associated with caregiving. Involving your child in routines and planning can increase a child's independence and confidence. This also will create structure into adulthood and the transition to managing their own care.
  - **Tips for time management:**
    - List day-to-day activities - incorporate the child or adult you are caring for and delegate tasks where possible.
    - Use a calendar system.
    - Consistency is key!
- **Self-Care:** Remember to take care of yourself. Prioritize rest, nutritious meals, exercise, and emotional well-being. Pay attention to your own healthcare needs.
  - **Tips:**
    - Plan time for pleasant activities, (e.g., going for walks, reading, shopping, getting a massage, or traveling). Ask yourself "What activities do I enjoy the most, and how can I fit them into my day?"
    - Self-care does not have to be expensive - light a candle or listen to your favorite song.
    - Practice mindfulness and meditation - take time by being fully present and aware of where you are.
    - Engage in hobbies and interests.
    - Prioritize social connection.
    - Provide self-compassion/positive affirmations.
    - Try journaling.
    - Practice relaxation techniques.
- **Accept your Emotions:** It is normal to experience a range of emotions related to caregiving. This can include feeling stressed, frustrated, and sad. Allow yourself to feel these emotions and seek support when needed.
- **Seek Professional Help:** Consider getting help through therapy or counseling to help alleviate and manage your stress.
- **Financial Planning:** Create a budget and explore financial assistance options or government programs that can help offset the costs.

Resources:

- **Sickle Cell Disease Association of America (SCDAA):**
  - Visit their website to find a chapter or support group.
  - National site: sicklecelldisease.org
  - Mobile chapter: scdmobile.org
- **Facebook Groups:** Search for groups like "Sickle Cell Warriors" or "Sickle Cell Community" to connect with others.
- **Local Hospitals and Clinics:**
  - Many healthcare institutions offer support groups for patients and caregivers. Check with the healthcare providers or hospitals in your area.
  - Engage in research studies to help progress the treatments for SCD!
    - Research is happening now at the Strada Patient Care Center.
      - Coping groups for children with sickle cell disease ages 6-18. Email Katey for more information: khayes@health.southalabama.edu
      - Brief cognitive screening for youth with and without sickle cell disease ages 6-16. Email Jasmin for more information: jhp2021@jagmail.southalabama.edu or sign up here: forms.gle/kGRiJGTtczxeHruR7
- **Seeking Professional Help:**
  USA Psychological Clinic
  6300 USA Health Blvd., Mobile, AL
  251-460-7149

  Veterans Recovery Resources
  1156 Springhill Ave., Mobile, AL
  251-405-3677

Make a Gift Today!

Give online at usahealthsystem.com/give

USA HEALTH
JOHNSON HAYNES JR., M.D.
COMPREHENSIVE SICKLE CELL CENTER

I am a: (Please check all that apply) ❑ Friend ❑ Parent ❑ Grandparent ❑ USA Employee ❑ USA Alumni

Name(s): _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Email: _____

I wish to make a gift to the University of South Alabama as follows:

Gift Purpose: ***(Check all that apply)***

❑ Johnson Haynes Jr., M.D., Memorial Fund

❑ Dr. Cecil L. Parker Jr. Sickle Cell Disease Distinguished Lectureship Endowment

❑ Watson Henderson Higher Achievement Award

❑ This gift is in honor/memory (circle one) of: _____

Please notify: _____

❑ Please list my/our name as follows: _____

Gift or Pledge Amount:

❑ I am making a one-time gift of: $ _____

❑ I pledge $ _____ per month to be deducted from my credit card or checking account.

Please continue monthly deductions as follows:

❑ Until I provide notification to stop OR ❑ until _____ (month/year)

Gift Fulfillment:

❑ My check is enclosed (Please make checks payable to Johnson Haynes Jr., M.D., Comperhensive Sickle Cell Center.)

❑ Please charge my credit card (check one) ❑ Visa ❑ Mastercard ❑ Discover ❑ AmEx

Card number _____ Exp. date _____ Name on card _____

Matching Gift Information:

❑ I work for _____(company name), which has a corporate matching gift program and will match this gift. Obtain appropriate forms from your HR department and mail to the USA Health Development Office.

Signature: _____ Date: _____

Return this form and payment to: USA Health Development
650 Clinic Drive, TRP III, Suite 1500 | Mobile, AL 36688 | 251-460-7032

Thank you for your consideration.

USA HEALTH
JOHNSON HAYNES JR., M.D.
COMPREHENSIVE SICKLE CELL CENTER
2451 University Hospital Drive
MCSB 1530
Mobile, AL 36617

Non-Profit
U.S. POSTAGE
PAID
Mobile, AL
Permit No. 506

SCDAA
"Break The Sickle Cycle"®

Sickle Cell Center announces leadership changes

The Johnson M. Haynes Jr., M.D., Comprehensive Sickle Cell Center recently announced two leadership promotions. Antwan Hogue, M.D., was named the center's medical director, and Ardie Pack-Mabien, Ph.D., FNP-BC, was named director. Both had been serving in interim roles since Haynes' passing in December 2022.

In addition, Hogue is a senior hospitalist and associate professor of internal medicine at the University of South Alabama's Frederick P. Whiddon College of Medicine, where he completed medical school. After a residency at the University of South Carolina School of Medicine, Hogue returned to his hometown of Mobile and USA Health.

"Dr. Hogue is a dedicated and compassionate clinician-leader who brings valuable perspective and insights into the role," said Nasser Lakkis, M.Sc.-M.D., FACC, chair of USA Health's department of internal medicine. "He will continue the tradition of excellence that started under Dr. Haynes, and he is committed to upholding the highest standards of care to our sickle cell patients."

Hogue met Haynes during his undergraduate years at USA. "I understand that I have giant shoes to fill," he said. "I am honored to have worked alongside him and to have witnessed many of the strides he made throughout his career."

Pack-Mabien, who was named director of the center, has served as a nurse practitioner specializing in pediatrics and internal medicine there since 1997.

"She is an administrative director who clearly understands the cultural, social and healthcare nuances relevant to those affected by the condition," Lakkis said. "She is pivotal to our robust research portfolio in sickle cell disease at USA. We are very fortunate to have her."

Pack-Mabien also worked closely with Haynes. In 2012, they and others at the center developed the pediatric to adult care transition program, which helps younger patients learn the importance of continuity of treatment in their next stage of life.

"In his honor and out of great respect for Dr. Haynes, the staff and I are highly motivated to continue his legacy," she said. "We are highly focused on providing quality, compassionate, and evidence-based care for our patients, as well as promoting sickle cell awareness in the community."