How Is Sickle Cell Anemia Treated?

Sickle cell anemia has no widely available cure. However, treatments can help relieve symptoms and treat complications. The goals of treating sickle cell anemia are to relieve pain; prevent infections, organ damage, and strokes; and control complications (if they occur).

Blood and marrow stem cell transplants may offer a cure for a small number of people who have sickle cell anemia. Researchers continue to look for new treatments for the disease. Infants who have been diagnosed with sickle cell anemia through newborn screening are treated with antibiotics to prevent infections and receive needed vaccinations. Their parents are educated about the disease and how to manage it. These initial treatment steps have greatly improved the outcome for children who have sickle cell anemia.

Specialists Involved

People who have sickle cell anemia need regular medical care. Some doctors and clinics specialize in treating people who have the disease. Hematologists specialize in treating adults and children who have blood diseases or disorders.

Treating Pain

Medicines and Fluids
Mild pain often is treated at home with over-the-counter pain medicines, heating pads, rest, and plenty of fluids. More severe pain may need to be treated in a day clinic, emergency room, or hospital.

The usual treatments for acute (rapid-onset) pain are fluids, medicines, and oxygen therapy (if the oxygen level is low). Fluids help prevent dehydration, a condition in which your body doesn’t have enough fluids. Fluids are given either by mouth or through a vein. Your doctor may prescribe antibiotics if you have an infection.

Treatment for mild-to-moderate pain usually begins with acetaminophen (Tylenol®) or nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen.

If pain continues or becomes severe, stronger medicines called opioids might be needed. Talk with your doctor about the possible benefits and risks of taking strong pain medicine, especially if the medicine will be used for a long period.

Hydroxyurea
Severe sickle cell anemia can be treated with a medicine called hydroxyurea (hi-DROK-se-yu-RE-ah). This medicine prompts your body to make fetal hemoglobin. Fetal hemoglobin, or hemoglobin F, is the type of hemoglobin that newborns have.

In people who have sickle cell anemia, fetal hemoglobin helps prevent red blood cells from sickling and improves anemia.

Taken daily by mouth, hydroxyurea reduces how often painful sickle cell crises and acute chest syndrome occur. Many people taking
A Letter from the Board Chairman

Dear Friends:

The American Sickle Cell Anemia Association (ASCAA) is a nonprofit 501 © 3 organization that was established in 1971 to provide education, testing, counseling and supportive services for the population at risk for sickle cell disease. Sickle Cell Disease (SCD) is a term describing a group of inherited disorders of the red blood cells. It is among the most prevalent of genetic diseases in the United States. The condition is most common among African-Americans in the United States, individuals with heritage from Spanish-speaking regions of the Western Hemisphere (South America, Cuba and Central America), Saudi Arabia, India and Mediterranean countries such as Turkey, Greece and Italy may also be affected. Currently, it is estimated that eight percent of the African-American population carries the gene for sickle cell trait. While more than 1,000 babies are born with sickle cell disease annually.

In 2013 ASCAA’s five regional counties (Cuyahoga, Lake, Geauga, Lorain and Medina) continued to place high emphasis on the provision of services that are culturally competent, family centered and community based. By sustaining its community-based partnership with the Ohio Department of Health, Cleveland Clinic, United Way Services, Cleveland Community Development Block Grant, individual and private donors all regional programs have received the education, testing and counseling service that make up our ASCAA service continuum. To date, we have seen a marked increase in the number served by our community awareness campaigns that focus on sickle cell disease and other hemoglobin disorders. The association’s keen attention to the cultural and linguistic needs of consumers of diverse racial and ethnic backgrounds has also been a fundamental practice in our counseling and educational services. In addition, during this period ASCAA continues to provide educational information as requested throughout the world.

Hence, the core feature of this Annual Report illustrates the programmatic, fiscal overview and the donors committed investment of ASCAA during 2013.

On behalf of the Board and staff of American Sickle Cell Anemia Association, we encourage you to continue supporting this organization in its efforts to one day eradicate sickle cell disease. Please feel free to contact us with your question and comments.

Sincerely,

Pamela Bradford, L.I.S.W., B.C.D., C.S.W.M
Board Chair
Board of Trustees

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Pamela Bradford - Board Chairman  
Dr. Anthony Stallion - Vice Chairman  
Dr. Mark Worford - Treasurer  
Ed Scott - Vice Treasurer  
Judy Montfort - Secretary

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Medical Advisory, Board Development  
Finance, Fundraising  
Personnel, Fundraising  
Fundraising, Program, Board Development

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Brandi Dobbs, NP  
Earsler Lesure  
Lisa Hackney, M.D.
ASCAA provide vital diagnostic testing for newborns, parents, adults, Head Start centers, Health Clinics and the general public. ASCAA currently tests more than 4,000 individuals annually.

ASCAA provides in-house and community outreach counseling to those affected by sickle cell disease and its variants, as well as information to those who want to learn more about the effects of the illness on individuals, friends and their families.

ASCAA provides educational presentation to students, teachers, social workers, physicians, the media and general public. Since its inception, ASCAA has distributed over 480,000 educational packages locally and globally.

C.H.A.M.P.P.S., which stands for Choosing Health Awareness Mobility Personal Power and Success, is a youth program designed for children and teens with sickle cell disease and other hemoglobin variants of the disease.
Financial Review

The American Sickle Cell Anemia Association 2013 Audit can be viewed on its website. The report can also be viewed on GuideStar.

Major Funders:
City of Cleveland/ (Community Development Block Grant)
Cleveland Clinic Foundation
Ohio Department of Health
United Way Services

Major Contributors:
Calvary Baptist Church
Enterprise Holdings, Inc.
Prayer Unlimited
Lutheran Community Foundation
Epsilon Lambda Omega
Chapter (In Memory of Ms. Karen Adkinson)
Attorney Leah Williams
Dr. Mark A. Worford

Financial Summary

Based on 2013 unaudited financials

American Sickle Cell Anemia Association is a nonprofit organization that holds a 501 © status

Total Operating Income: $330,200
Operating Expenses: $326,470
Total Operating Less Expenses: $3,730

Grants: 80%
Special Events: 3%
Donations: 15%
Other: 2%

Programs: 85%
Administrative: 12%
Special Events: 2%
Other: 1%
General Donations

AAA Mid Atlantic
AAA Mid Atlantic - NJ
AAA Mid Atlantic - DE
Abbott Laboratories
Kwabena Afriyie
Sharisse Ajibade
Sara Alexander
Dorothy J. Allison
Allstate (Employee Giving Campaign)
Samoanna Anderson
Grace Andrassy
Anonymous
AT&T (UW Employee Giving Campaign)
William Baker
William Beverly
Sheila Blade
BOA (United Way Campaign)
Norman & Deborah D. Bolden
Rochelle Boswell-Payne
Cynthia Bowien
Renee Boyd
Pamela Bradford
Mary L. Bradley
Ira Bragg-Grant
Michael Brandon
Valencia Brazzell
Donjuana M. Brown
Brenda Burston
Renee Burston
Ernest & Portia Buser
Regina Byrd
Cairo Elementary School
Paulette Canty
Sabrina B. Canty
Glen Carr
Leslie Carter
Louise Chandler
Kathleen Chiarucci
Beverly Clements
Irene P. Clements
Barri Cloud
Che’rri Colbert-Gunn
Sharon Coleman-Smith
Kari Cunningham, DMD
Constance Curry
Ronda Curtis
Robin Dace
William & Noma Davis
Dr. Teresa Dews
Betty Drain
Dupont Company
Dartny Ellis
El-Hasa Court 47 Daughters of Isis
Ernest & Portia Elly
Enterprise Rent-A-Car
(Stark County Locations)
Brian Everett
Janice Foster
Bernetta D. Foy
Kevin Fuller
Cierra Freeman
Deborah Friedman, MD
G.E. United Way Campaign
Darral Gaffney
Cheryl Gant
Phyllis Garrison
Leonard Goins
Becky L. Goodwin
Robert Grace
Marilyn C. Graham
Mark Grattan
Greater Cleveland Cemetery Assn.
Greater Cleveland Community Shares
Brandi Griffin
Almarita Hailes
Aliza G. Hamilton
Melissa Harris
Sabrina B. Harris
Patricia Harris
Michael Hawley
Sharonda Hayes
Cynthia Headen
Highmark Blue Cross/Blue Shield
Angelie Hillsman
Alan Hodes
Leman Hodes
Amber Holcomb
Torey Hollingsworth
Emery D. Holloway
Honeywell Hometown Solutions
Angelica Hopkins
Horseshoe Casino (Cleveland Hospira)
Paula Hubbard
Stephanie Hunter
Dehedgra Ido wu
Frances Jackson
Melissa Jackson
Sara Jackson
James Jameson
Norman & Deborah Jernigan
Jerusalem Christian Church
Margaret Johnson
Valincia Johnson
Arminta Jones
Cynthia Jones
Johnny Jones
Darlene Kemp
Edward King
Vanessa Lawson
Carleton Levert
Nicholas Loney
Stacey Lynch
Tamika Madden
Ellenia Matthews
Steven Mawhorter
Theresa McDade
Melissa Mebane-Rogers
Elesita Medalle
Velma Miles
Monique Miley
Cynthia Mitchell
Judy Montfort
Samantha Moon
Erica Moore
Gloria Moore
Angela Moss
Delma Moss
Cynthia Moxley
LaTonya Murray
Kevin Murray
Sherrill Nall
Nature Stone
Gregory Neal
A.G. Nelson
Eric Nelson
Network for Good
New York Life
Mylene Noir
Candace Nowell
Osyamwen Oghogho
James Oliver
Jonathan Parries
Parrish Hill Baptist Church
Ruth Patterson
Gilberto Pena
Coronel Penn
Marie Phillips
Sherry Phillips
Philomethean Club
Virgil Pittman
Melba Pritchett
Providence Baptist Church
Lynn Reed
Kasaundra Reed
Irene P. Register
Michael E. Register
Rani Rhodes
Marvin Richards
Angela Roberts
Antoinette Robinson
Samantha C. Scales
Michelle Schwartz
Barbara Sheffield
Dr. Duncan Shepherd
Eleeshia Simmons
Antoinette Smith
Dominque Smith
Hubert Smith, Jr.
Elise J. Smith-Fenton
Aliza Spencer
Eric Spencer
Melvin Spencer
Kirk Stewart
Brandon Stinson
Patricia Stokes
Reginald Stover
Otis J. Sturdvant
Kwabena Swan
SUM-Ohio St. Cleveland Headquarts.
SUM-The Federal Reserve Bank of Cleveland
SUM-The Lincoln Electric Company
SUM-Third Federal Savings & Loan Association
Stephanie Tate
Bruce & Alfreda Taylor
Yolanda Taylor
Third Fed. Savings & Loan Assn.
Cheryl Thomas
Kevin Thomas
Lucretia Thomas
Jimmy Tiggs
Paulette Tiggs
Michaune Tillman
Cheryl Towns
TRUST(Employee Giving Campaign)
Ira Tuttle
United Baptist Church
United Health Group
United Way-Dayton
United Way-Tampa
UW of California Capital Reg.
United Way of Central Indiana
UPS
UW of Greater Phil & S. NJ
UW of Hopeful-Prince George
LuAnn Wagner
Mary Wells
Paul Wells
Rendia Wells-Mitchell
Vera White
Lenore R. Whitfield
Hallely William
Caroline Williams
Julian Williams
Kevin Williams
Winifred Williams
Sonali Wilson
Atlee Wilson
LaTanya Winston
Kilanda Wooden
Mark Worford, D.D.S.
Jimmy Wright
Carolyn Young

Walmart Steel Yard Commons

Donations in Memory
Milton & Betty Afriyie (In Memory of Charles J. DiNenna)
Joseph & Lynda Berman (In Memory of Dr. Harold Ford)
Avis Blake-Thomas & Family (In Memory of Curly Mae Lunsford)
Joe & Kristin Buser (In Memory of Charles J. DiNenna)
Bob & Paula Canchola (In Memory of Julian Goins)
Viola Coles (In Memory of Delon L. Haamid)
Joe & Kristin Fuller (In Memory of Charles J. DiNenna)
Walter E. & Waltraud F. Grever (In Memory of Johnny L. Kelly)
Charles & Marsha Harrison (In Memory of Natasha Martin)
Patrick Herman (In Memory of Patricia D. Herman)
Terri & Bret Hernandez (In Memory of Julian Goins)
Willie Jane Hrabowkie (In Memory of David Emanuel Hrabowkie)
Diane K. Huston (In Memory of Charles J. DiNenna)
Betty B. Jernigan (In Memory of Charles J. DiNenna)
Rob Martin (In Memory of Natasha Martin)
Liz & Rey Medalle (In Memory of Julian Goins)
Ruth Melton (In Memory of Ms. Patricia Peterson)
Randy Presant (In Memory of Mrs. Erma Tucker)
Mary Pultz (In Memory of Eddy D. Leegrand)
Francie Roberts (In Memory of Julian Goins)
Floyd & Rosemary Sheppard (In Memory of David E. Hrabowkie)
Edwin Simmons (In Memory of Charles J. DiNenna)
Patricia Sintic (In Memory of Bianca Marie Smith)
Henry & JoAnn Slice (In Memory of Charles J. DiNenna)
Margaret Taylor (In Memory of Mrs. Erma Tucker)
Mark & Melissa Tuttle (In Memory of Roseann Vincent-Viosin)
Thomas & Mary Wilcock (In Memory of Julian Goins)
Diane Wright (In Memory of Charles J. DiNenna)

Donations in Honor
Crystal Lake Middle School (In Honor of Roseann Vincent-Viosin)
Second Calvary Misn. Baptist Church (In Honor of Mark Garrett)

In Kind Donations
Chick-Fil-A Harvard Park
Cristiano Print Solutions
Dr. Sheila Ferguson
East Mt. Zion Baptist Church
Fairview Park Target
Lake Metro Parks
New Life Deliverance Ministries
Omega Psi Phi Fraternity, Inc.
Pickwick & Frolic
STAPLES
Target-University Heights
Temple Emanu El
hydroxyurea also need fewer blood transfusions and have fewer hospital visits. Doctors are studying the long-term effects of hydroxyurea on people who have sickle cell anemia. Studies in very young children have shown that hydroxyurea can be given safely and that it improves anemia and hemoglobin F levels while treated with hydroxyurea suggest that those treated with the drug survive longer than those not treated with the drug. Hydroxyurea can reduce the number of white blood cells in your blood, which can raise your risk for infections.

People who take hydroxyurea must have careful medical follow-up, including blood tests. The dose of this medicine might need to be adjusted to reduce the risk of side effects. A doctor who has knowledge about hydroxyurea can tell you about the risks and benefits of taking this medicine.

Preventing Complications
Blood transfusions are commonly used to treat worsening anemia and sickle cell complications. A sudden worsening of anemia due to an infection or enlarged spleen is a common reason for a blood transfusion.

Some, but not all, people who have sickle cell anemia need regular blood transfusions to prevent life-threatening problems, such as stroke, spleen problems, or acute chest syndrome. Having routine blood transfusions can cause side effects. Examples include allergic reactions and a dangerous buildup of iron in the body (which must be treated). In general, the blood supply is fairly safe from infections such as hepatitis and HIV.

Infections
Infections can be a major complication of sickle cell anemia throughout life, but especially during childhood. Often, infections can be prevented or treated. To prevent infections in babies and young children, treatments include:

• Daily doses of antibiotics. Treatment may begin as early as 2 months of age and continue until the child is at least 5 years old.
• All routine vaccinations (including a yearly flu shot), plus the pneumococcal vaccine.

If your child has sickle cell anemia and shows early signs of an infection, such as a fever, you should seek treatment right away. Adults who have sickle cell anemia also should have flu shots every year and get vaccinated against pneumonia.

Eye Damage
Sickle cell anemia can damage the blood vessels in the eyes and the retinas. The retinas are the thin layers of tissue at the back of the eyes. Regular checkups with an eye doctor who specializes in diseases of the retina can help detect eye damage.

Strokes
Stroke prevention and treatment are now possible for children who have sickle cell anemia. Starting at age 2, children who have sickle cell anemia should have routine ultrasound scans of the head. This is called transcranial Doppler (TCD) ultrasound. These scans are used to check the speed of blood flow to the brain. TCD scans allow doctors to find out which children are at high risk of stroke. Doctors can
treat these children with routine blood transfusions to reduce the risk of stroke. A doctor who has knowledge about blood transfusions and sickle cell disease can tell you about the benefits and risks of this treatment.

**Treating Other Complications**

Acute chest syndrome is a severe and life-threatening complication of sickle cell anemia. If acute (sudden) failure of the liver and kidneys also occurs, it’s called acute multiple organ failure. Treatment for these complications usually occurs in a hospital and may include oxygen therapy, blood transfusions, antibiotics, pain medicine, and balancing body fluids. Leg ulcers (sores) due to sickle cell anemia can be very painful. Ulcers can be treated with cleansing solutions and medicated creams or ointments. Skin grafts might be needed if the leg ulcers are ongoing. Bed rest and keeping the legs raised to reduce swelling are helpful. If you have a lot of pain from leg ulcers, your doctor may recommend a strong pain medicine. Your doctor might recommend gallbladder surgery if the presence of gallstones leads to gallbladder disease. Priapism (a painful erection in males) can be treated with fluids, medicines, or surgery.

**Regular Health Care for Children**

Children who have sickle cell anemia need routine health care (just like children who don’t have the disease). They need to have their growth checked regularly. They also need to get the routine shots that all children get. All children younger than 2 years old should see their doctors often. Children who have sickle cell anemia may need even more check-ups. After age 2, children who have sickle cell anemia may not need to see their doctors as often, but they usually still need checkups at least every 6 months. These visits are a time for parents to talk with their child’s doctor and ask questions about the child’s care. Talk with your child’s doctor about eye checkups and whether your child needs an ultrasound scan of the brain. Until age 5, daily penicillin is given to most children who have sickle cell anemia. Doctors also give many children a vitamin called folic acid (folate) to help boost red blood cell production. Young children who have sickle cell anemia should have regular checkups with a hematologist (a blood specialist).

**New Treatments**

Research on blood and marrow stem cell transplants, gene therapy, and new medicines for sickle cell anemia is ongoing. The hope is that these studies will provide better treatments for the disease. Researchers also are looking for a way to predict the severity of the disease.

**Blood and Marrow Stem Cell Transplant**

A blood and marrow stem cell transplant can work well for treating sickle cell anemia. This treatment may even offer a cure for a small number of people. The stem cells used for a transplant must come from a closely matched donor. The donor usually is a close family member who doesn’t have sickle cell anemia. This limits the number of people who may
have a donor. The transplant process is risky and can lead to serious side effects or even death. However, new transplant approaches may improve treatment for people who have sickle cell anemia and involve less risk.

Blood and marrow stem cell transplants usually are used for young patients who have severe sickle cell anemia. However, the decision to give this treatment is made on a case-by-case basis.

Researchers continue to look for sources of bone marrow stem cells—for example, blood from babies’ umbilical cords. They also continue to look for ways to reduce the risks of this procedure.

**Gene Therapy**

Gene therapy is being studied as a possible treatment for sickle cell anemia. Researchers want to know whether a normal gene can be put into the bone marrow stem cells of a person who has sickle cell anemia. This would cause the body to make normal red blood cells.

Researchers also are studying whether they can “turn off” the sickle hemoglobin gene or “turn on” a gene that makes red blood cells behave normally.

**New Medicines**

Researchers are studying several medicines for sickle cell anemia. They include:

• Decitabine. Like hydroxyurea, this medicine prompts the body to make fetal hemoglobin. Fetal hemoglobin helps prevent red blood cells from sickling and improves anemia. Decitabine might be used instead of hydroxyurea or added to hydroxyurea.

• Adenosine A2a receptor agonists. These medicines may reduce pain-related complications in people who have sickle cell anemia.

• 5-HMF. This natural compound binds to red blood cells and increases their oxygen. This helps prevent the red blood cells from sickling.
ASCAA Mission:
The American Sickle Cell Anemia Association was incorporated in 1971 as a nonprofit organization. The mission of the organization is to provide comprehensive education, testing, counseling and supportive services to the population at risk for sickle cell anemia and its variants. Further, its intent is to ensure quality and quantitative care in the provision of comprehensive service to affected individuals and families.

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