

Sickle Cell

September is National Sickle Cell Awareness Month

Sickle Cell Sunday minority blood donation outreach campaign

The West Central Ohio Comprehensive Sickle Cell Center is a Regional Sickle Cell Project (RSCP) funded by a grant from the Ohio Department of Health, Maternal, Child and Family Health, Sickle Cell Services Program. The RSCP is administratively located inside of Dayton Children’s Hospital. This year, we are collaborating with the Community Blood Center of Dayton in an effort to increase awareness and education about the need for minority blood donations for adults affected by sickle cell disease. Both adult and pediatric patients with sickle cell disease may have to receive frequent blood transfusions to help manage their disease and to prevent serious complications including stroke, acute chest syndrome, severe anemia, and other health-related issues associated with having sickle cell disease.

Sickle Cell Sunday Minority Blood Donation Campaign is a coordinated, cooperative effort between the Ohio Department of Health (ODH), state-funded Regional Sickle Cell Projects (RSCP), regional blood programs in Ohio (participation may vary) and various statewide and/or local faith-based groups or organizations.



The goal of this initiative is to educate and increase awareness about sickle cell disease, sickle cell trait, and the need for minority blood donors in the African American and Hispanic communities. Sickle Cell Sunday is observed annually in Ohio, on the third Sunday in September during National Sickle Cell Awareness Month. We encourage members of African American and Hispanic churches/faith-based organizations to participate in this statewide initiative. **All religious denominations and/or faith-based organizations are encouraged to participate.**

the role of the african american church



The African American church has historically been the primary institution servicing the religious, social, political, economic, and psychological needs of its members, as well as the African American community at-large.

Even today, the African American church remains the fundamental institution and first place of worship, guidance, support, awareness and education, and promoting the holistic health and well-being of its members.

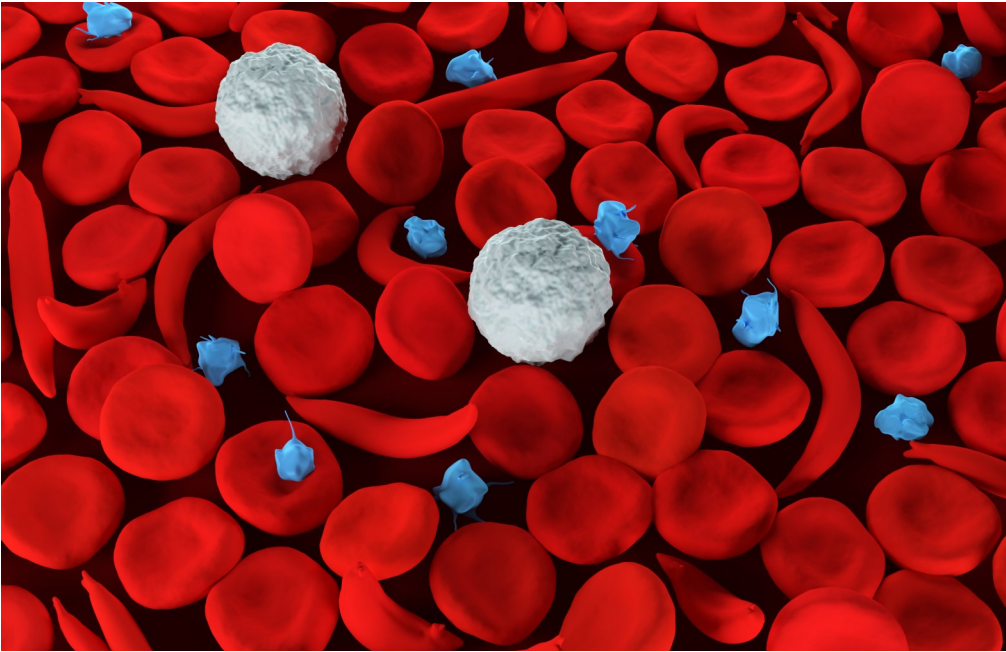
“Beloved, I wish above all things you may prosper and be in health even as your soul prospers.”

3 John 1:2 (KJV)



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facts about minority blood donations and sickle cell disease

- A red blood cell has over 300 proteins on it, called markers. Ancestry is a marker.
- If you have African ancestry, you can make a difference in the life of an individual living with sickle cell disease by donating blood. It all comes down to genetics.
- Blood donors play an important role in sickle cell disease treatment. Individuals affected by sickle cell disease may often require blood transfusions to treat and/or prevent sickle cell disease related complications, especially strokes, severe anemia, acute chest syndrome, and priapism (in men).
- Blood that closely matches an individual's ethnicity is less likely to be rejected by the person, and provides fewer risks for complications.
- Generally, the best blood match for a patient requiring ongoing transfusions comes from donors of the same ethnic or genetic background.
- For this reason, it is extremely important to increase the number of available blood donors from all ethnic groups.
- According to the latest data, African Americans comprise nearly 13% of the United States population, but only 5% of the donor population compared to caucasians who comprise of more than 72% of the donor population.
- Due to medical advances, children with sickle cell disease are becoming adults. This brings on new disease complications that may be managed by frequent blood transfusions.

facts about sickle cell trait (SCT)

- Sickle cell trait is not a disease nor will it turn into sickle cell disease.
- It is important for both parents to know if they have sickle cell trait before making reproductive choices.
- If both parents have sickle cell trait there is a 25% (1 in 4) chance with each pregnancy of having a child with sickle cell disease.
- About 1 in 13 Black or African-American babies is born with sickle cell trait.
- Individuals with sickle cell trait can donate blood.

facts about sickle cell disease (SCD)

- Sickle cell disease is a term used to describe a group of inherited blood disorders affecting the red blood cells.
- Sickle cell disease is a life-long condition characterized by pain, anemia, and other life-threatening complications. Individuals with sickle cell disease make red blood cells that contain an abnormal hemoglobin called hemoglobin "S."
- Hemoglobin "S" causes the red blood cells to form a "sickle" or crescent moon shape which becomes hard, sticky and difficult to pass through small blood vessels.
- Sickle cell disease affects African Americans at a higher rate. Individuals with heritage from Spanish-speaking regions in the Western Hemisphere (South America, Cuba, and Central America), Saudi Arabia, India, and Mediterranean countries such as Turkey, Greece, and Italy are also affected.
- According to the Centers for Disease Control (CDC) and Prevention sickle cell disease:
 - Affects approximately 100,000 Americans in the United States
 - Occurs among about 1 out of every 365 Black or African-American births
 - Occurs among about 1 out of every 16,300 Hispanic-American births

blood bond

Antonio Jr. and Sydnei Copher

The sounds of harmony hangs in the air at the Copher house – violin, flute and ballet for Sydnei, 15, and piano for Antonio Junior, 16. The love of a, b, c, d, e, f, g – the seven notes of music – are in their blood. That’s not the only blood-bond the two siblings share; they also share sickle cell disease, a blood disorder impacting their red blood cells.

Synthia Copher first found out that she was a carrier for sickle cell disease when she was in elementary school. But after her and her husband, Antonio, lost a child Antonio was tested, and they discovered he was also a carrier. They were told that their children would have a one in four chance of having the disease.

Sickle cell disease causes the body to make sickle-shaped red blood cells. “Sickle-shaped” means that the red blood cells are shaped like a crescent. Normal red blood cells look like doughnuts without holes in the center. The shape allows the cells to move easily through your blood vessels.

Sickle cells are stiff and sticky. The sticky cells can block blood flow in the blood vessels, which can cause organ damage and can cause those with the disease to go into a sickle cell crisis. A sickle cell crisis is marked by severe pain throughout the body as the blood cells “stick together,” trying to move through the body.

Both siblings are “frequent flyers” at Dayton Children’s, being hospitalized numerous times throughout their life with a sickle cell crisis. Last year, Antonio was inpatient six times. Prior to that, Antonio had gone years without being hospitalized.

“There’s not really a rhyme or reason for the crisis,” he says. “But the doctors attribute it to significant swings in the weather and a big growth spurt.”

Both siblings are excited to serve as Dayton Children’s ambassadors to help



them continue to create a sense of understanding and harmony for others who have the same condition.

“They will say ‘sickle cell has me, but it doesn’t stop me,’” Synthia says. “I think that’s so powerful because despite the pain and sometimes setbacks, they don’t miss a beat.”

Both Antonio Jr. and Sydnei regularly see Mukund Dole, MD, pediatric hematologist and oncologist and program director of the West Central Ohio Comprehensive Sickle Cell Center, who helps manage their sickle cell disease. Antonio is also closely watched for asthma and minor kidney issues. Antonio Jr. started taking piano lessons five years ago from an instructor at Stivers, where his sister Sydnei attends high school and is actively involved in the orchestra and dance.

“Piano calms me when I’m feeling bad,” says Antonio. Sydnei shares her brother’s sentiments, “Music and dance make me feel free,” she says. “I can’t have a bad day when I’m floating in the air.”

Growing up, they learned something was different when they wanted to try different activities like track and field and had to sit out in gym class. They were quickly encouraged by their mom to try something else, like music. “I remember getting really winded when I was on the playground around kindergarten and asking my mom why,” Antonio shares. “We started to

understand that we weren’t like other kids that could run and jump, but we could play music.”

Giving back is contagious in the Copher house. Synthia’s focus on the positive led her to get involved in the sickle cell advisory committee, become a parent partner at Dayton Children’s and join the Midwest Ohio sickle cell collaborative. Last year, Antonio Jr. donated a generous portion of his earnings from his first job to the West Central Ohio Comprehensive Sickle Cell Center. And Sydnei has been actively involved in volunteering at the Foodbank after the tornadoes struck Dayton over Memorial Day.

“Getting involved in our community gives us an outlet to share our story of hope with others,” she said. “I want other moms to know that although their child may have this illness, some days will be hard and you will spend time in the hospital, but you will survive this.”

When Antonio was first diagnosed at his newborn screening, I remember being very overwhelmed about what I read online, I was so worried that he wouldn’t live a normal life,” Synthia shares.

Though they knew the risks, they experienced shock and a ‘d’jà vu moment’ when they welcomed Sydnei into the world and learned she too had sickle cell disease.

Though both teens suffer from a life-long condition, most would never know based on their positive attitude and active roles in the community. “It took me awhile to flip my attitude from one of fear and worry for my kids into something positive,” Synthia shares. “And my positive attitude caught on. Both kids are actively involved in volunteering in the community and raising awareness about sickle cell disease.”

activities for sickle cell awareness month and Sickle Cell Sunday



- Educate yourself and others about sickle cell disease and sickle cell trait.
- Motivate your members to support those affected by sickle cell disease by donating blood.
- Host a health fair and invite a speaker to talk about sickle cell disease and blood donations.
- Donate to the Regional Sickle Cell Project or take up a special offering for patient care.
- Promote Sickle Cell Awareness Month during the month of September.
- Encourage everyone to wear burgundy ribbons and/or attire on Sickle Cell Sunday.
- Hold a candle light ceremony to honor those who lost their battle with sickle cell disease.
- Sponsor a blood drive at your place of worship by calling the Community Blood Center at 937-461-3220, or visiting www.givingblood.org/formoreinformation. (Restrictions may apply.)

West Central Ohio Comprehensive Sickle Cell Center

The West Central Ohio Comprehensive Sickle Cell Center's mission is to provide continuing, coordinated, and comprehensive care to children and adults with sickle cell disease, sickle cell trait, and other hemoglobinopathies. The center coordinates the Ohio Newborn Screening Program for infants identified at birth with a hemoglobin disorders. The counties served include, Allen, Auglaize, Champaign, Clark, Darke, Greene, Hancock, Hardin, Logan, Mercer, Miami, Montgomery, Paulding, Preble, Putnam, Shelby, and Van Wert.

For more information contact:

Cynthia Moon, MSE

Regional Sickle Cell Project Director

West Central Ohio Comprehensive

Sickle Cell Center

One Children's Plaza, Dayton, Ohio 45404

937-641-5014 or 1-800-228-4055 ext. 5014

moonc@childrensdayton.org

about the Community Blood Center

- CBC reaches 12 counties in Ohio and 3 counties in Indiana
- CBC serves 23 local, surrounding hospitals. We need 250 blood donors every day to meet local needs.
- Donating blood is a simple way for you and your family to help others. Remember, there is no substitute for blood for those who need it, and humans are the only source for human blood. That's why becoming a blood donor is so critical to so many people. You can safely donate red blood cells every eight weeks (56) days.

To schedule an appointment:

- Go to www.donortime.com. Look up your zip code to find a community drive near you and schedule an appointment.
- Go to the Dayton Community Blood Center at 349 South Main Street, Dayton, Ohio 45402.
- Call 937-461-3220 to schedule an appointment at the center or at a community drive.

