Sickle cell is the most common genetic blood disease in the country. But awareness is far too uncommon.
Sickle cell disease is a genetic disease that affects the red blood cells. There are many different forms of sickle cell (including Hemoglobin SS, Hemoglobin SC, and Sickle Beta Thalassemia), but in general, they all cause these cells to form in the shape of a “sickle.” When this happens, the blood has difficulty flowing through the body, which causes severe pain and even organ damage.

Care and quality of life for sickle cell patients has dramatically improved since the 1970s, but current life expectancy is still only 39 years, exactly half of the 78 years for average Americans. However, recent studies have shown that the latest standards of care, focused on prevention and consistent treatment, can greatly increase both the quality and length of life for sickle cell patients. Unfortunately, many health care professionals have insufficient knowledge about appropriate treatment guidelines. Standards of care and expected outcomes vary widely across the country.

How do you get sickle cell disease?

Sickle cell disease is a genetic disease, and you cannot catch it from another person. You must have two sickle cell genes—one from your mother and one from your father—in order to be born with the disease. If you only have one gene, then you have sickle cell trait. People with sickle cell trait do not show any symptoms, but they can pass the disease to their children if their partner also has sickle cell trait. Approximately 1 in 12 African Americans have sickle cell trait, but very few black Arkansans are aware of their trait status. Although people with sickle cell trait do not have symptoms, they should know their status and understand the risk for their children. A simple and inexpensive test can tell you whether or not you and/or your partner risk passing on the disease to your children.

Who is affected by sickle cell disease?

People of all races and ethnicities are affected by sickle cell disease, and it...children outside of Pulaski County and adults living with the disease have very few options for quality care.
affects millions of people worldwide. In most regions, however, it disproportionately affects people of African descent. In Arkansas, more than 98 percent of sickle cell patients are African American. Experts estimate that there are currently between 1,000 and 1,250 people living with sickle cell disease in the state, mostly concentrated in the Southern, Eastern and Central counties. All children that are born with the disease are referred to Arkansas Children’s Hospital for care. However, children outside of Pulaski County and adults living with the disease have very few options for quality care. Many physicians have little or no experience treating sickle cell patients, and health care providers may not be aware of the current standards of care.

Because sickle cell disease is most prevalent in minority populations, the treatment, or lack of treatment, often highlights the racial and ethnic health disparities that exist across the country. A study from the American Journal of Preventive Medicine reported that parents of children with sickle cell disease often face more barriers to quality treatment than parents of children with other ailments, including long waits in both inpatient and outpatient settings and difficulty scheduling appointments. Although timely treatment can often minimize the need for extensive and expensive therapies, these inefficiencies and barriers to care often intensify the problems that the patients are facing.
Gabrielle Brumfield, new to the world in 1994, was unaware that she would be on a journey that would forever affect her life—Gabrielle was diagnosed with Sickle Cell Disease.

Her mom, Krystie, was shocked because she didn’t have the sickle cell trait but she had a different type of abnormal gene, the hemoglobin C trait. Gabrielle’s dad had the sickle cell trait.

“I was upset when I found out,” said Krystie. “How can she have sickle cell when I don’t have sickle cell trait, but they told me that children can get the disease when they receive one abnormal gene from each of their parents.”

Doctors started Gabrielle on penicillin and folic acid. She was taken off penicillin at six years old. Since then Gabrielle admits the road has been difficult.

“It’s been hard… there are certain things it [sickle cell] doesn’t allow me to do. I can only run for a short period of time because my legs will start hurting,” said Gabrielle.

She says that many people at her school have never heard of sickle cell and she is the only one at her school with the disease. However, she points out that her friends and classmates are extremely supportive.

“They may ask ‘are you ok, is it your sickle cell, are you hurting what do we need to do,’” she said.

Her mom also points out that Gabrielle handles her disease well. “It’s much better now than when she was six or seven years old, times that she goes into crisis are also few and far between.”

Krystie says to increase awareness of sickle cell disease and to influence change in health care services, policy makers and all Arkansans must be educated about sickle cell.

“Not just from literature or television” she said. “But see our children, talk to our children…walk a day in our shoes.”

Gabrielle and her mom continue to educate themselves about the disease by participating in the Sickle Support Services Summer Camp. Youth and their parents at the summer camp not only have fun and play games but they learn coping skills and receive information about the different types of sickle cell diseases. Parents and their children also receive additional support from other parents and children. The AMHC has sponsored the camp for the past two summers.

Wise beyond her years, Gabrielle now plays mentor to her younger cousin who also has the disease. “I tell him to talk to someone if he is in pain and not to keep it to himself if he is in crisis,” she said.

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The Arkansas Minority Health Commission would like to honor Germaine Johnson and our partners for their work in Arkansas in Sickle Cell Advocacy and Awareness. To learn more about Sickle Cell Support Services Summer Camp, visit sicklecellsupportservices.com or call 590-6943.

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**Sickle Cell Fast Fact**

One out of 12 African Americans has sickle cell trait, which is much more common than sickle cell disease (1 in every 400 African Americans). About 650 babies are born each year in Arkansas with sickle cell trait. This means 1 of about every 60 babies born in Arkansas has sickle cell trait.
September has been designated as “National Sickle Cell Month” in the U.S. The observance of this month originated in 1975, and a resolution was signed by President Reagan in 1983.

Sickle cell is often perceived as a “Black” disease, but this is not exclusively so. Yes, it is concentrated in Americans of African origin, it also occurs in many groups of people whose ancestors were Greeks, Italians, Latin Americans, Native Americans, etc, and not just in the U.S. This is a global disease.

Arkansas is making strides to address this disease. A Legislative Task Force was established during the 87th General Assembly to:

- Examine how the state of Arkansas responds to Sickle Cell
- Determine the best practices to treat Sickle Cell Disease
- Recommend more efficient methods for treating Sickle Cell Disease
- Recommend how to obtain more federal funds for treating Sickle Cell Disease and providing special education to children with Sickle Cell Disease
- Recommend to the General Assembly specific changes to the law that will improve treatment of Sickle Cell Disease and improve the provision of special education to children with Sickle Cell Disease.

To experience a glimpse of this disease, I interviewed a local resident who is known as “The Voice of Sickle Cell”, and he also serves as the Chair of the Legislative Sickle Cell Task Force, and Founder & President of Sickle Cell Support Services, Mr. Germaine Johnson Sr., and asked him to share a few thoughts with us. Listed below are excerpts from our conversation:

**Describe how living with this disease has impacted your life**

“I was born with the most severe form of sickle cell a chronic transfuser. This disease has limited me physically. It alters every aspect of my life. Although sickle cell has many negatives, it has also taught me to persevere, to believe in more than myself, and depend and trust God.”

**What changes have you had to make to adapt?**

“There are many, but the major ones occur with my family and work. I have to schedule everything around my doctor visits. Transfusing even when I am not feeling well. I have missed many important events in my sons’ lives, and my wife and I have missed celebrating several of our anniversaries because of my hospitalizations.

**As a parent, how have you shared your experiences with your children?**

“I hope my sons have learned from me that God is first, and no matter how many stumbling blocks you encounter in life, you can turn them into stepping stones.”

**What were the deciding factors that lead you to become “The Voice of Sickle Cell?”**

“I didn’t DECIDE, I was purposed for it. Our family did as much as they could to assist us. I started hosting support groups for friends in ‘2001, and would hear stories of limited services/programs available. So I incorporated Sickle Cell Support Services to assist families like mine.”

The Arkansas Minority Health Commission is focusing on Sickle Cell Disease during this fiscal year in partnership with UAMS Partners for Inclusive Communities, Sickle Cell Support Services, and the Arkansas Legislative Task Force on Sickle Cell. We began the month with a media campaign titled, “The Face of Sickle Cell.” This campaign was launched on local television, and radio spots. The goal of this campaign is to inform Arkansans about the truth of Sickle Cell Disease and the importance of knowing your individual sickle cell status.

As we commemorate this month with a focus on sickle cell disease, The Arkansas Minority Health Commission released a Sickle Cell Outreach request for application on September 17. Successful grant applications will be funded up to $25,000 to non-profit or public agencies to address education and awareness, support for families with sickle cell, and collaboration /partnership with health care professionals.

Together, we can improve the health of those living with sickle cell disease in Arkansas. We invite you to join in the fight. Join us at Philander Smith College on September 30 for the Sickle Cell Roundtable.
Mark Your Calendars

Arkansas Minority Health Commission

with Partners for Inclusive Communities,
Sickle Cell Support Services
and the Legislative Task Force on Sickle Cell Disease

present the

“Sickle Cell Roundtable”

Join us to discuss how we can improve the quality of life for people with sickle cell disease in Arkansas.

September 30, 2010
11am-1pm
Philander Smith College
Donald W. Reynolds Library
& Technology Center Conference Room
Lunch will be provided

Arkansas Legislative Task Force on Sickle Cell Disease

Please RSVP to 501-686-2720 or 1-877-264-2826
The Arkansas Minority Health Commission (AMHC) is pleased to announce that it is seeking applications from community and faith-based non-profit organizations for funding programs that advance a greater understanding of sickle cell trait and disease (SCT/D) throughout Arkansas.

The purpose of the grant is to further the AMHC’s mission and strategic plan of increased education and awareness regarding sickle cell trait and disease prevention. In addition, this grant strives to improve the quality of life for Arkansans living with sickle cell disease and prevent more children from being born with the disease. Due to the disproportionate disparities associated with SCT/D, this grant program strives to address high-risk minority communities and build capacity among community based organizations that can reach the target populations by:

- Improving community understanding of SCT/D through education and awareness campaigns.
- Increasing the number of minority Arkansans who have been screened for SCT/D and know their status.
- Increasing access to support services for patients and families affected by SCT/D.
- Increasing the number of support groups and organizations focused on SCT/D prevention, education, and care.

Improving the quality of life for people with sickle cell disease and increasing prevention requires interventions on individual, family, and community levels, including:

- People living with sickle cell disease
- Family-members of people with sickle-cell disease
- People with sickle cell trait, and
- Members of affected populations.

Therefore, AMHC encourages broad participation by eligible candidates to assist in reaching its mission and goals.

Visit arminorityhealth.com for more information and to obtain a copy of the AMHC Sickle Cell RFA and application.
This issue:

Dr. Joycelyn Elders
A bridge to Healthier Living
Putting the pieces together

A publication of the Arkansas Minority Health Commission

Health Care Access:
28% of nonelderly African Americans and 40% of nonelderly Hispanics are uninsured in Arkansas.
Source: Kaiser Family Foundation

82% (114,844) of black children live in low-income families

Quality Health Care:
More minorities state that people like themselves are treated less fairly when seeking health care, specifically, 40% of urban blacks, 29% of rural blacks and 25% of Hispanics.

42% (199,879) of white children live in low-income families

82% (114,844) of black children live in low-income families

Source: Arkansas Racial and Ethnic Health Disparity Study II: A Minority Health Update, Arkansas Minority Health Commission

Behavioral:
More than 73% of African Americans are overweight or obese; compare to 66% of all Arkansans.
Source: 2008 Behavioral Risk Factor Surveillance System-Arkansas

Watch for our “Face Sickle Cell” media campaign!

Sickle cell disease affects us all. So why don’t we know more about it? It’s time to face the facts. So we can fight the disease.

1-800-342-2923

and the Legislative Task Force on Sickle Cell Disease