

Having a newborn baby can be a difficult adjustment for parents – lack of sleep, midnight feedings, incessant crying. But what's even more difficult for any parent is caring for a sick child. And in the African American community, one in 500 children is born with sickle cell disease.

Dr. Betty S. Pace has made it her life's work to find a cure for the disease. Growing up in the small town of Racine, Wisconsin, she knew a large family who lost four young children to sickle cell disease.

"One was a good friend of mine, and she died in junior high school. I remember visiting her when she was bedridden from having a stroke," Pace said. "It really had an impact on me."

Sickle cell disease is an inherited red blood cell disease caused by a genetic error in a person's hemoglobin, which makes the red blood cells inflexible and sickle shaped. This leads to blockages in blood vessels and prevents oxygen from reaching the body's tissues. Side effects of the disease include swelling of the spleen, which occurs when the sickle blood cells get caught in the spleen and cause it to expand like a balloon; pain and inflammation, which happen when blood flow is cut off from the body tissue and organs; anemia; jaundice; and stroke.

"The best way to prevent death in children with sickle cell disease is diagnosis in infancy," said Pace, who *Popular Science* magazine named in 2004 one of the United States' "Brilliant 10" scientists. "If children with the disease are given penicillin twice a day from 3 months to 5 years, the rates of death and infection are significantly decreased."

Although there is still no universal gene therapy-based cure for sickle cell disease, Pace said that recent educational initiatives targeting parents have doubled the life expectancy of those with sickle cell disease. "We teach parents how to react to the disease symptoms. If their baby has a fever, they're told to bring the baby to the emergency room immediately because the child may have an infection. We also teach parents how to feel the spleen to see if it is enlarged," said Pace.

The average life span for individuals with sickle cell disease is 42 years for men and 46 years for women; and while the present state of the disease is challenging, Pace has confidence in the future. New, promising drugs are under development; and effective treatments continue to lengthen life expectancy. "It's my job to help people understand the process of the disease," said Pace. "I try to help parents so they don't feel like they're on this mission alone."

Betty S. Pace, M.D.

Researcher and Director, University of Texas at Dallas Sickle Cell Disease Research Center

Residence: Dallas, Texas

Research



Sickle Cell Disease

"The best way to prevent death in children with sickle cell disease is diagnosis in infancy."

FACT

In the United States, about 1,000 babies with sickle cell disease are born each year.

February 2006

STAGE OF LIFE – *First Years*

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
			1 1902: Langston Hughes, poet, born.	2 1915: Biologist Ernest E. Just receives Spingarn Medal for research in fertilization and cell division.	3 1956: Autherine Lucy enrolls as the first black student at the University of Alabama.	4 1913: Rosa Parks, civil rights pioneer who sparked 1955 Montgomery, Alabama, bus boycott, born.
5 1884: Willis Johnson patents eggbeater. 1934: Hank Aaron, major league home-run champion, born.	6 1993: Arthur Ashe Jr., tennis player, humanitarian and activist, dies.	7 1883: Ragtime pianist and composer Eubie Blake born.	8 1968: Three South Carolina State students killed during segregation protest in Orangeburg, South Carolina.	9 1964: Arthur Ashe Jr. becomes first black on U.S. Davis Cup team.	10 1927: Leontyne Price, internationally acclaimed opera singer, born. 1992: Alex Haley, Pulitzer Prize-winning author, dies.	11 1990: Nelson Mandela of South Africa is released from prison after 27 years.
12 Lincoln's Birthday 1909: NAACP founded in New York City 1927: Xavier University of Louisiana College of Pharmacy founded.	13 1970: Joseph L. Searles becomes first African American member of New York Stock Exchange.	14 Valentine's Day 1817: Frederick Douglass, "the Great Emancipator," born.	15 1961: U.N. sessions disrupted by U.S. and African nationalists over assassination of Congo Premier Patrice Lumumba.	16 1874: Frederick Douglass elected president of Freedman's Bank and Trust.	17 1938: Mary Frances Berry, first woman to serve as chancellor of a major research university (University of Colorado), born.	18 1931: Toni Morrison, winner of 1988 Pulitzer Prize for her novel <i>Beloved</i> , born.
19 1919: First Pan-African Congress, organized by W.E.B. DuBois, held in Paris.	20 Presidents' Day 1895: Frederick Douglass, leading voice in the abolitionist movement, dies.	21 1965: Malcolm X assassinated in New York.	22 Washington's Birthday 1899: Col. Frederick D. Gregory becomes first African American to command a space shuttle mission.	23 1868: W.E.B. DuBois, scholar, activist and author of <i>The Souls of Black Folk</i> , born.	24 1864: Rebecca Lee Crumpler becomes first black woman to receive a medical degree (New England Female Medical College).	25 1853: First black YMCA organized in Washington, D.C.
26 1965: Civil rights activist Jimmie Lee Jackson dies after being shot by state police in Marion, Alabama.	27 1897: Marian Anderson, world-renowned opera singer and civil rights activist, born.	28 1984: Michael Jackson, musician and entertainer, wins eight Grammy Awards.				



The U.S. Postal Service unveiled the Sickle Cell Disease Awareness Commemorative stamp in September 2004 to educate the public about the disease and promote finding a universal cure.

African American History Calendar
www.aetnaafricanamericancalendar.com

We want you to knowSM
Aetna