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HEADLINE: Sickle cell survival rate high in state; Death rate far lower than U.S. average for black children

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BODY:

Young black children in Maryland appear to survive sickle cell disease at a rate that is strikingly better than those in other states with large black populations, a new study has found.

In Florida, by contrast, black children ages 1 to 4 appear to die from the disease at more than double the national rate, according to a federal scientist.

The research, reported yesterday in the government journal Public Health Reports, was based solely on death certificates and did not explain the disparity between states.

The death rates in Pennsylvania and Virginia also were much better than the national average, which is 6.8 deaths for every 1,000 "person-years." That is a way to measure the time American children lived with sickle cell disease.

Sickle cell is an inherited disease that primarily afflicts black Americans, affecting about one in every 350 black newborns. Abnormally shaped red blood cells can become stuck inside their capillaries, causing severe pain. Children are particularly vulnerable to life-threatening infections and are prescribed daily antibiotics until age 5 to increase their survival chances.

Maryland's low rate — less than one death per 1,000 person-years — was not easy to explain.

Dr. Samuel Charache, a leading sickle cell researcher who recently retired from the Johns Hopkins School of Medicine, said one explanation may be a state program in which all newborns are tested for the disease before they leave the hospital.

Those testing positive are given antibiotics to prevent pneumonia, a frequent killer of people afflicted with the disease. Families are directed to programs of continuing care, and parents are instructed to contact a doctor immediately when their children have flare-ups.

"The mechanics of the program are very good, and the follow-up is very good," Charache said.

However, Charache said he found it hard to believe that Maryland's death rate was so much lower than the national average. He said it was also puzzling that Maryland's rate was less than one-eighth the rate in California, which also screens all newborns.

Dr. **Susan Panny,** who heads the newborn screening program for the Maryland Department of Health and Mental Hygiene, said she was not surprised by the difference between the rates in Maryland and California.

In California, she said, "they're finding the kids with sickle cell disease at birth, too," she said. "They tell the parents and the doctors, but that's pretty much it. Here we follow the children closely and make sure they get all the vaccinations and care that they need."

To some extent, the differences might also be a statistical fluke, perhaps rooted in local differences in the way causes of death are recorded on death certificates. In Maryland, for instance, it is common to list pneumonia, kidney failure or other fatal complications of sickle cell as the cause of death. Other states might designate sickle cell.

Problems with immigrants

One theory to explain Florida's high rate — 16.2 deaths per 1,000 person-years — is that the state must struggle to reach immigrants, particularly Haitians.

Those who are not identified do not get the daily antibiotic treatment needed to increase their chances of surviving the rare genetic disease.

"They probably have more recent immigrants than any other sickle cell program in the country," said Dr. Kwaku Ohene-Frempong, medical director of the Sickle Cell Disease Association. "The barriers to health care that new immigrants have may actually be impeding the ability to get care."

"It's reasonable for the people in Florida to be somewhat concerned," said Dr. Harold Davis of the Food and Drug Administration, author of the study. He also urged researchers to investigate sickle cell programs in Maryland and Pennsylvania because "you would think something must be going on right there."

Scientists also reported in the journal that:

Although rare, sickle cell causes 75,000 hospitalizations a year, mostly for acute pain, at a cost of $475 million. The government pays two-thirds of the bill.

An Illinois study found that 4 percent of adult patients accounted for one-fourth of that state's sickle cell hospitalizations. Some were hospitalized dozens of times.

More survivors nationwide

Nationwide, an increasing number of young children are surviving sickle cell, Davis found. He checked death certificates of black children ages 1 to 4 from 1968 to 1980 and from 1981 to 1992. Deaths from the disease were 35 percent lower in the later period.

But when Davis examined the 18 states with the greatest number of young black children, he found startling differences. However, his study did not explain the geographic disparities.

Davis said Pennsylvania's figures were more statistically sound than Virginia's.

'Serious situation'

Pennsylvania also has a state screening program that may contribute to better survival. Every sickle-cell newborn and mother is placed immediately in an expert's care, said the sickle-cell society's Frempong.

Previously, many inner-city babies fell through the medical system's cracks because their mothers had no permanent doctors to whom the hospital could send sickle-cell test results, said Frempong, sickle cell chief at Philadelphia's Children's Hospital. The plan ensures that babies get treated and that mothers get sickle cell education before leaving the hospital.

Davis found that young black Florida children without sickle cell died of other diseases — excluding trauma, prematurity and birth defects — at a rate 27 percent higher than the nationwide rate. In Pennsylvania and Maryland, mortality from other diseases was slightly lower than in the rest of the nation.

Davis cautioned that his findings must be verified, and Florida plans to do so immediately .

"This is a serious situation," said Dr. Jim Howell, the state's health officer. He said it was just a theory that reaching immigrants was the problem and added, "We are going to fully investigate this."

Sickle cell death rates

Death rates of black children ages 1 to 4 from sickle cell disease in 18 states, according to a study in the journal Public Health Reports. The rates reflect deaths per 1.000 "person-years," and were calculated using death certificates from 1981 through 1992.:

United States: .. ..6.8 deaths per 1,000

Alabama: 6.4

California: 8.7

Florida: 16.2

Georgia: 10.5

Illinois: 7.5

Louisiana: 7.8

Maryland: 0.8

Michigan: 5.1

Mississippi: 6.2

New Jersey: 6.2

New York: 6.0

North Carolina: 5.8

Ohio: 5.1

Pennsylvania: 3.2

South Carolina: 5.6

Tennessee: 9.1

Texas: 8.1

Virginia: 3.2

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